Cass Business School
CITY UNIVERSITY LONDON

# The UK Care Economy:
## Improving outcomes for carers

Carers UK commissioned this piece of work from Les Mayhew in order the look at the various challenges that families are currently facing, with large societal changes underway and new demographic pressures, we wanted an expert's view on the various contexts and opportunities for improving outcomes for carers.

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# Foreword

The demographic reality of growing care needs at a time of shrinking resources is one of the biggest public policy challenges of our time.

Alongside a deeper understanding of how families and public services are being affected by this challenge, fresh thinking is needed in debates on how services, benefits and workplaces all need to adapt to meet it.

In this report, Professor Mayhew examines the landscape of care and support now and explores how the care economy could benefit from different approaches. Several key messages emerge.

Firstly, from a services perspective, there is much more we could be doing to understand local populations and tailor support to need, as well as removing barriers that so often stand in the way of families getting the right support at the right time. We also need to map outcomes from services far better, and understand how additional support in one service can deliver savings in another. This is particularly important as local and national governments develop new NHS, public health and health and wellbeing structures across the country.

Secondly, with more and more families providing care to different generations simultaneously, new approaches should be developed to deliver 'whole-family' services which look at childcare, domestic support, eldercare and workplace support in the round.

Crucially, this all means we must position care firmly in the economic context, and as an economic contributor rather than a drain on the public purse. Investing in care in the right way and reconfiguring services can help families stay in work alongside caring, deliver higher workplace productivity and staff retention for employers whose staff are struggling to juggle work and care and also provide opportunities for growth in the care market.

Finally, as the Government implements one of the most widespread reforms of the benefits system in decades, the financial support they receive is also at the forefront of many carers' minds. As we analyse the impact of changes and cuts to welfare, Professor Mayhew's exploration of different ways in which the tax and benefits system could support families who care, will also contribute to debate about support for carers in the future shape of welfare.

**Heléna Herklots, Chief Executive, Carers UK**

CARERS UK
the voice of carers

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# The UK Care Economy
# Improving outcomes for carers

## Executive summary

Carers are the largest source of care and support in the UK. The aims of this research are to identify broadly defined economic outcomes in the caring system from the point of view of carers and how they can be improved.

Our approach has been to recognise that the supply and demand for care are determined by the:

- quantity of care needed and available,
- costs and rewards (financial and other)
- productivity of carers
- information provided by people giving, receiving, planning and funding care

This is not to suggest that individuals exercise free choice and only decide on economic grounds. Decisions are circumscribed and determined by factors to do with individual carers and the needs of the people caring and being cared for, local circumstances including the availability of care services and support, and also Government policy on care.

At a macro level we find that the UK economy is likely to grow more slowly in coming years due to global shifts in economic power and changes to its demographic structure. The greatest increase in the demand for care will come from an ageing population. On the other hand we argue that the current arrangements operate perversely to discourage optimal care arrangements.

The overall direction of public policy appears to be towards greater individual responsibility and local decision making. With the frontiers of the welfare state receding in areas such as social care and benefits, it is falling to families and households to absorb a majority of any additional burden either financially or through providing care in kind.

However, changes in family structures, the emergence of pivot generations (caring for people older and younger than themselves simultaneously), wide variations in income and wealth and increased cultural diversity make for an increasingly complex care economy.

Related to the repositioning of the state, there are a number of interconnected issues that will change the shape of how care is provided. These range from the future role of local authorities in the assessment and delivery of social care, to issues to do with adequacy of the supply of care workers, their levels of training and the quality of care provided.

A crucial element will be the relationship between social care and the NHS. It has been argued more people face crisis situations as result of trends in care assessment towards only providing support for those in greatest need coupled with

early discharge from hospital. However, the evidence points in the direction of providing more low level preventive services and earlier intervention as a means of managing future demand.

The social impact of these changes can be mitigated if people work for longer and there are jobs for them to do. However, they also need to remain healthy for longer because healthy people are more likely to be in work and a healthier population requires fewer carers. To maintain and improve health requires changes of behaviour at an individual level but also new mechanisms that reward health or reduce future health and social care costs.

It is generally accepted that older and disabled people want to live independent lives at home or in the supported housing of their choice for as long as possible. A key challenge therefore is how to offer low-cost solutions from multiple providers which are personalised to meet the service users' needs. This requires much better information built around individuals receiving care as well as the organisations providing the care.

We identify low or stagnant productivity in care providing services as another key challenge. Services are commissioned and channelled into peoples homes through a range of organisations. Limited or at best inefficient information sharing between providers and care recipients and their families limits the scope for closer working and care planning. A consequence is that services are not as integrated or responsive enough or as efficient as they could be.

One of the themes identified is a tendency for over-specialisation not only between health and social care but also within each through a sub-division of roles and responsibilities. The burgeoning of different types of specialist provider in both health and social care can damage productivity though increasing the volume of unnecessary home visits etc.

How care is organised could also be improved by looking at different ways of supporting disabled and older people in our communities. For example, care could be better supported by local authorities without them necessarily being responsible for the care they provide. This could be through mechanisms such as providing expert advice and signposting services to providers.

An example is 'time-banking' which enables individuals to earn 'time credits' for their time spent caring for others in which they are able to 'withdraw' their time when they need something done themselves. Time banks measure and value all the different kinds of help and skills we can offer each other. In a time bank, reciprocity is formalised with everyone becoming both a giver and a receiver.

Although they cannot be regarded as complete substitutes for home visits, assisted living technologies offer the potential for improved quality of life for people that are confined to their homes. These can deliver services which entertain, educate and stimulate social interaction, provide services which encourage users to get fitter and to adopt healthier lifestyles and enable older and disabled people to work from home.

The research identifies several barriers to change one of which is a lack of statistical information to inform local services. Although national surveys of carers exist, local information about unpaid carers and patterns of unpaid care is limited to the Census. In addition, information on carer services provided by the private and voluntary sectors is incomplete and often incoherent. Much better use could be made of local administrative information by combining information in health and social care.

A barrier to change and an impediment to improved efficiency is that NHS and local authorities maintain separate records on hospital admissions, community health visits, and care packages, all of which could be easily unified using NHS numbers to create a singly sourced care record. The immediate impact would be better case management, and an ability tailor support packages in home or other settings.

The same information would also provide a platform for strategic needs assessments at local level and would fit well with the Health and Wellbeing Boards being established as part of the NHS reforms. However, in the process of reorganisation, there is a danger that a 'data iron curtain' could develop between key organisations and stakeholders making the job even harder because information may be locked in silos.

A system of integrated care records fits well with the enabling roles of assisted living technologies which have the potential to contribute to higher productivity. The barriers to their wider adoption are partly technical and partly cultural. Generations approaching the dependency phase of life will be more technology literate than their predecessors and so find it easier to learn how to make best use of the technology.

For prevention services to work, care assessments need to be timelier and faster reacting which in turn requires better risk profiling and case finding. Transitions into care and then into end of life can occur suddenly and are times of heightened stress for carers and so the need for support can change rapidly.

With funding pressures in local authorities it can be argued that the incentives are the exact opposite, i.e. to delay assessments and raise the thresholds at which social care is provided. This is counter-productive if the result is to increase the subsequent needs for crisis interventions and hence greater healthcare costs.

Carers now have more statutory rights at work that help to meet these needs and so these barriers are slowly being dismantled. However, there remain barriers of a financial kind that make it unprofitable to work without some addition financial support. At the macro level, for example, the efforts of carers remain totally unrecognised in measures of GDP.

The limited nature of Carer's Allowance, the main carer's income replacement benefit for carers who are unable to work full-time because of substantial caring responsibilities does not always help people stay in work or find work. There is scope for examining a different and complementary policy aim through a 'Care Credit', which could also help with care costs but the new credit would be more aimed at helping people to mix care with work.

The final barrier is the sheer complexity of the system. The welfare system is a perplexing mix of client groups, funding streams, assessment criteria, delivery organisations, care professions and care settings. There are also different care philosophies about how care should be provided and financed e.g. through personalised budgets, in kind, at home or in institutions; whether benefits should be based on entitlement or taxed; and tensions between provider organisations especially, health and social care.

Some of this complexity goes with the territory and diversity can be strength but only if it is surrounded with clear advice and signposting to resources available locally. The more complex a system is the more information, support and advice that is

needed to make it work smoothly. The tendency is for all organisations, Government included, to make it more complex than it needs to be.

In summary, the research finds that a good outcome for carers is one that meets their needs as well as the needs of the person being cared for. These outcomes can be measured in financial or career terms in cases where work and caring are balanced or in emotional terms, in terms of duty of care real or otherwise, or the health and well-being of the carer. These outcomes would have a better chance of success if there were some simplification and reforms particularly to the benefits system and to the way health and social care are financed and managed and some suggestions are provided.

# The UK Care Economy ~ Improving outcomes for carers

## 1. Introduction

### 1.1 Background

Carers are the largest source of care and support in each area of the UK. The aims of this research are to identify broadly defined economic outcomes in the caring system from the point of view of carers and how they can be improved. Outcomes are circumscribed and determined by factors to do with individual carers and the needs of the person being cared for, local circumstances including the availability of external care services and support, and also Government policy on care.

Although there was a change of Government in 2010, the policy context is not disputed, particularly the observation that everybody will be a carer at some point in their lives. The previous Government observed that society is changing rapidly and that "most people are living longer, many are developing long-term clinical conditions and the vast majority have rising aspirations in terms of maintaining maximum independence and control over their own lives". [1]

The Coalition Government echoes a similar theme but importantly notes that:[2]

> "…….there are difficulties in focusing on evidence of improved outcomes for carers from single carer-specific 'interventions'. Rather the evidence from research shows that effective support to carers usually goes beyond a single intervention and encompasses good quality mainstream services, and sensitive and carer-aware professional practice (across health, social care, education and all local services). As importantly, evidence shows that a joint strategic approach by health, local government and voluntary organisations is needed for a local population to develop and commission a range of local services suited to the local needs of carers and people using services."

A further important development is that the Government has declared its intention to shift power away from Whitehall to "those who know best what will work in their local communities – and carers are key players in their local communities in terms of their knowledge and experience and are very resourceful in finding practical solutions".

This shift will be shaped and directed by giving local government an enhanced role in health with responsibility for leading Joint Strategic Needs Assessments along with GP-led Clinical Commissioning Groups, developing shared priorities and strategies across social care, the NHS and public health, and in doing so addressing cross-cutting issues such as support for carers. Plainly, it will be important that carers are involved in this process by drawing on their experience, knowledge and expertise.

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[1] Carers at the heart of 21st-century families and communities

[2] Recognised, Valued and Supported: Next Steps for the Carers Strategy

In this research, we analyse whether we are prepared for the massive changes ahead, particularly those that result from an ageing population. In doing so we look at how the system currently works, what is being achieved and what changes are needed to improve outcomes from a carers' perspective. Our central thesis is that demand for care will grow massively in the next decades primarily as a result of people living longer. We further observe that although people are living longer their health life expectancy is not rising as fast as life expectancy. This poses significant strategic issues because it means that more people will require care for longer.

We note that there has been an incremental moving back in the frontier of state support with implicit or explicit transfer of responsibility for care to individuals, their families or local communities. These changes have occurred often for good reasons for example because of better treatments, or improved delivery of services. Examples include shorter lengths of stay in hospital or avoiding inappropriate admission into nursing care, the closure of large mental hospitals or end of life strategies that enable people to die at home. However, the impact on families is not always recognised or accounted for.

As more people recuperate or spend their last years of life at home so the demand for care in home settings increases. Although there is evidence that remaining at home is supported by patients and improves well-being, the practical effect is that some of the burden of care post discharge or pre-admission to nursing care falls onto unpaid family carers as well as the cost. Social Services have limited budgets and so do not have unlimited capacity to satisfy all demand and so the combined effect is likely to be a continuing increase in the demand for unpaid care and professional care.

Tangible examples may be observed in the way care is financed and supported by the tax payer. Clients are assessed for eligibility for social care using the FACS (Fair Access to Care Services framework) which has four bands: critical, substantial, moderate and low. It is evident that many local authorities are operating at 'substantial' and above and a very significant number of local authorities will only consider clients banded as critical due to shortages of resources.

After several previous reviews of how long term care is to be financed, the Commission on Funding Care and Support reported in July 2011 and recommended sweeping changes to the present system, in particular the balance between public and private finance for long term care. At the same time, radical changes are planned for the social security system of welfare benefits and tax credits.[3] A system of Universal Credit is being introduced which will roll into one existing income related benefits and tax credits in which the basic principle will be to 'make it pay to work'.

The pension age for women was already being increased in steps from age 60 to 65 between 2010 and 2020 to the same age as for men currently. Under the latest legislation, state pension age will increase to 66 between 2018 and 2020. There are also proposals for increases to age 67 from 2026 to 2028 and then for further increases thereafter. One practical effect of state pension and social security changes will be that for some people, mostly women, it will become financially more difficult to stay at home to care for a chronically ill spouse, frail relative or disabled child for example.

[3] Another significant change is the announcement of the closure of the Independent Living Fund to new applicants. The ILF was set up to enable disabled people to live independent lives in their community rather than in residential care in which payments are used to pay a care agency or employ someone to provide personal and domestic care.

Together these add up into hugely significant changes to the welfare state and what people can expect in later life especially at ages when their health and social care needs are greatest. The inescapable message is that people will have to work longer and eschew previously higher levels of and different types of social security benefits, while at the same time being available to provide care for family members which the state can longer afford to provide.

These changes may be difficult and challenging at a time of chronic economic constraints and the currently massive public expenditure deficit. They are also precipitating opportunities for wider reforms in order to break down barriers, inefficiencies and waste in the system i.e. to re-think care afresh. However any reforms need to take place against a background of slower economic growth but also a population which is both increasing and ageing.

It can be assumed that these economic and demographic facts will act as a catalyst for a rolling series of reforms over coming decades the net effect of which are likely to result in further frontier shifts. The gradual withdrawal of the state will thus have significant consequences for demand, especially for unpaid care. This will lead to difficult choices between working and caring; at the same time the price of paid care could rise due to shortages of care workers and increased demand.

On the supply side we need to consider the balance between paid and unpaid care, how care is delivered, and also crucially productivity issues which are part of the solution for meeting future demand. On the demand side, we need to look at demographic trends including health status, but we also need to understand households in greater detail since these will become the main vehicles for delivering care in future.

Our research looks at these questions from a carer's perspective and asks what can be done to improve the care economy and outcomes for carers, making it more sustainable. The first sections of the paper seek to pull together three key aspects of the problem: it considers the demographic drivers for care at the level of the population, families and individuals; secondly, how paid and unpaid care interacts in macro-economic terms; and thirdly the present role played by the benefits system in supporting carers.

Subsequent sections consider strategies for meeting the future demand for care from four perspectives: prevention strategies that improve health and delay the onset of disease; the scope for productivity improvements to the current system of care; institutional barriers to improved efficiency and better carer outcomes; and finally policies that provide support to carers.

### 1.2. Defining terms

In setting the scene, we adopt a broad definition of care as well as a narrower definition. For the purpose of estimating care needs and resources available to give care, it is useful to have a dichotomous approach: either someone is a carer or they are not based on the quantity and the nature of the activity they provide. In reality, care intensity is a continuum, from making or receiving a phone call – 'caring about' - through to living with someone and giving them support twenty-four hours a day – 'caring for'.[4]

[4] Mooney, A. and J. Statham with A. Simon (2002). The pivot generation Informal care and work after fifty. Bristol: Policy Press

There are also important issues about what roles people who give or receive care expect themselves or others to play. With the perception of care as being 'women's work', the role of women plays a big part in any analysis but so do issues of socio-economic group. More affluent people tend to pay for care whilst black and minority ethnic people are more likely to provide unpaid care, often because formal services are or are seen to be inappropriate.[5]

In analysing the contributions of paid and unpaid care there are also questions about whether like is being compared with like. Caring for children, for example, is put in a different category to caring for disabled people or much older and frail people. Even if apparently similar activities are being compared, when giving and getting a service from a relative or an employee of a care provider there are qualitative and other differences.

Central to understanding the connection between activities and relationships is that what many disabled and older people want to achieve or maintain is independence. Either having a care worker or a relative as an unpaid carer can reinforce or undermine independence. This complexity underlines that any economic analysis of caring has to ensure that there is not an unintended financial cost to choosing the option that maximises utility or quality.

In this context, the broad definition looks at the overall amount and nature of care, whether it is bringing up children or managing a family; however, the narrower and more usual definition is the provision of support to people who have disabilities, poor health or both. For example, the 2001 Census defined unpaid care as:

> 'Any unpaid help, looking after or supporting family members, friends, neighbours or others because of long-term physical or mental ill-health or disability or problems related to old age'

Adopting a broad as well as a narrow definition enables us to look at situations in which a carer combines bringing up children whilst looking after an elderly parent or a sick spouse. Such situations arise more frequently as a result of changes in family demography and increased life expectancy; but as people live to very old ages we find that the supply of family carers may dry up and so the total care commitment becomes important.

According to the recent survey of carers in England[6], common reasons why care is required included a physical disability (58%), a long-standing illness (37%) or a sight or hearing loss (20%). A majority (62%) of carers looked after someone whose condition affected them only physically, 11% said the cared for person was affected only mentally and 22% said both physically and mentally.

It can also be noted that 'ill-health' and 'disability' are also, in part, social constructions. That is to say they are partly the result of how people define and perceive themselves and others but also they reflect the way that society is organised. As proponents of the social model of disability argue, people may have

[5] See e.g. http://www.equalityhumanrights.com/key-projects/how-fair-is-britain/online-summary/care-and-support/

[6] Survey of Carers in Households - 2009/10 England. Department of Health, 2010. http://www.ic.nhs.uk/pubs/carersurvey0910

impairments but it is environments that disable them.[7] The implication is that as social and physical environments change, so does the demand for care which is why, for example, home adaptations are an important part of the mix.

**1.3 Trends ageing and health**

The demographic trends are particularly challenging. The UK is going through a very rapid period of population growth from around 55.9m in 1980 to a projected 71m by 2030. The demand for care from adults with physical or learning disabilities is likely to increase in proportion to the numbers of people in each age group and so will not be the main driver of growth in the future. Instead, this will come from the growth in the number of older people age 65 + whose number will double from 8m in 1980 to 16m in 2030.

The ratio of people aged 20-64 to those aged 65+ peaked in 2008 at 3.7 and is now in long term decline and set to reach 2.5 by 2030, so there will be fewer younger adults to provide potential support. This ratio is usually used to measure the pension burden, but if we arbitrarily take the critical age of dependency as being 80+ and the support ratio as being the number of 20-79 year olds to those aged 80+, the ratio falls from 15 to 9 over the same period.

This ratio can be further unpicked to show that the support ratios in terms of 20-29, 30-39 and 40-49 years olds to the 80+ population falls further and faster than the ratio of 50-59, 60-69 and 70-79 year olds. A key implication of this is that the average age of carers is likely to increase with time in addition to there being relatively fewer carers overall within the age group that is growing fastest. Also, carers will remain in paid work longer themselves as pension age increases.

An older population usually spells a lowering in average levels of health, but if health improves the demand of care is changed for the better. The issue therefore is whether additional life years are being spent in good or poor health. The projections reported in this paper suggest that whilst healthy life expectancy is increasing it is not increasing as fast as life expectancy. The implication is that as the gap widens a greater proportion of the population will need care at any point in time.

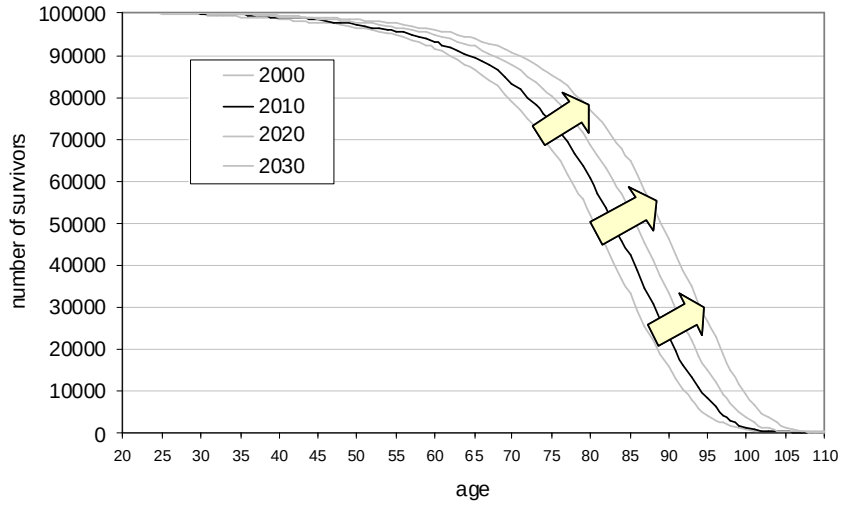
Currently, we estimate that there are approximately six healthy adults to every one adult in poor health albeit with different levels and types of dependency. With ageing population and no improvement in health this ratio could fall to four. Currently, healthy life expectancy at age 20 in the UK is 50 years but to stabilise the ratio at 6 where it is today healthy life expectancy at age 20 would need to increase to 55 years. The question is whether this is achievable or not.

Projections of healthy life expectancy indicate that by 2030 it will reach 52.4 years based on this trend. However, 52.4 years is still 2.6 years below where it needs to be to sustain the ratio of health to unhealthy people at the level of 6. The reason is that life expectancy is progressing at a slightly faster rate than health life expectancy. This is attributable in part to the success of health care for keeping people alive for longer especially in the management and treatment of long term conditions such as heart disease, but there are also other factors.[8] The effect of this will be seen in a gradual

[7]Swain, J., S. French, C. Barnes, C. Thomas. Disabling Barriers, Enabling Environments**.** London: Sage.

[8] See Mayhew, L. (2009) Increasing longevity and the economic value of healthy ageing and working longer. London: Cass Business School.

increase in the population who are living longer but with long term medical conditions.




**Box 1: Current and projected UK survivorship**

Larger numbers of people will survive to older ages as is shown in the projected survival curves above.

A survival curve shows the number people surviving to each year of age in ten year intervals from 2000 to 2030 starting at age 20.

The scale is initially fixed at 100,000 lives, which are then progressively reduced through death.

The direction of the arrows suggests a 'frontier of survival' that is rapidly developing into uncharted territory especially after age 65.

The number of older people age 65 + will have at least doubled from 8m in 1980 to 16m in 2030.

The increases in life expectancy are reflected in the significant reduction in mortality at older ages. One of the most important findings is the increasing life expectancy of males which is forecast to catch up with females between 2020 and 2025. The reasons are that male life expectancy has benefited from the decline in smoking related diseases and the reduction in employment in heavy industry and other hazardous occupations. Life expectancy for a male turning 50 will be around that of females who are expected to live for 35 years. This compares with a male life expectancy of only 22.5 years in 1960, a difference of 12.5 years. Clearly, closing the gap could have implications for caring if it resulted in shorter spells apart at the end of life.

The second trend that is clear from life tables is a growth spurt in the survival of the oldest old (see Box 1). So for example our work suggests that a male that reaches age 50 in 2020 will have a 4.5% chance of reaching 100 as compared with a female who would have an 8.8% chance. This compares with only 0.54% for males and 1.7% for females in 2001 and 0.014% and 0.098% in 1951. For those turning 80 the

odds of reaching 100 years are even better with a male having a 6.4% chance of reaching 100 and a female a 12.3% chance.

We can be fairly certain about these trends since they are part of an unbroken pattern spanning the last fifty years, but noticeably accelerating particularly after 1970 when effective treatments for long term conditions started to have an impact. We also know from other countries which are some years ahead of UK trends that more people living to older ages is a biological fact. Clearly, changes on this scale pose have massive implications for the UK care economy.

**1.4 Estimates of the numbers of carers**

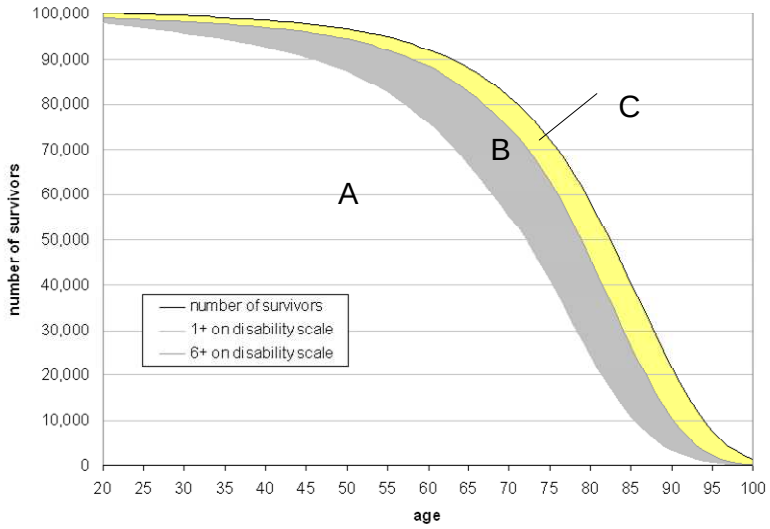
Caring in the narrow sense itself can be sub-divided into low or high intensity caring activities where for example, befriending would be regarded as low intensity and feeding, dressing and bathing or constant supervision as high intensity. People who care can be divided into three categories: people who are paid to provide social care, those who provide support as volunteers and, finally, the unpaid support from family, close friends and neighbours.

Estimates of the number of people across these three groups who provide care in society, need to take account of the time spent caring and the type of care provided and so there are many different ways of reporting figures. They can be based on whole time equivalent (WTE) units assuming a defined number of hours per week, usually 40; or based on the minimum number of hours of care provided, say 20, which would give double the number. They can also be based on official definitions such as entitlement to benefits or types of care package.

To put this in a wider perspective, we find that the people classed as 1+ on the scale are generally out of work and claiming long term sick a disability benefits. Those who are 6+ claim Disability Living Allowance or Attendance Allowance, and people who are 7+ on the scale is correlated with the number receiving long term care. Previous work by Nuttall et al on the financing of long term care estimated the number of hours of care per week that would be needed on average by any person using the same disability scale. [9] They assumed 5 hours of carer per week in categories 1-2, 15 hours in 3-5, 30 hours in 6-8, and 45 hours per week in 9-10. In 2010 this would imply that there is 3.0m whole time equivalent (WTE) carers based on a 40 hour week, rising by 2030 to 3.85m carers (see Box 2).

How many actual people are providing care is difficult to disentangle due to different reporting systems and definitions. ‘Skills for Care’, the body responsible for workforce development in adult social care in England, estimated that there were 1.75m paid jobs in adult social care in 2009 of which 1.25m or 72% were involved in directly providing care and support. The remainder consisted of 162,000 managerial and supervisory jobs, 110,000 professional jobs (including nurses, social workers, and occupational therapists) and 226,000 administrative, ancillary and other jobs.

[9] Nuttall, S. R., Blackwood, R. J. L., Bussell, B. M. H., Cliff, J. P., Cornall, M. J., Cowley, A., Gatenby, P. L. & Webber, J. M. (1994). 'Financing long-term care in Great Britain' *Journal of Institute of Actuaries*, 121, pp




**Box 2: Disability in the UK adult population (Key: (A) healthy; (B) 1 to 5; (C) 6+**

The Rickayzen Walsh model (2002) categorises people on a scale from zero to 10, in which zero is healthy and 10 is a person with only a few months to live. The above chart based on a survivorship life table for the UK splits the adult population into three groups.

People classed as 0 are healthy (A), 1 to 6 on the scale correlate with out of work and claiming long term sick or disability benefits (B); and 6+ with the number receiving social care (C). Somebody 9+ on this scale for example would be in their last year of life.

The estimated number of disabled adults in 2010, 2020 and 2030 are shown below based on stepped intervals on the disability scale. They allow for continuing health improvements (1 extra year in health expectancy at 20 every decade). Results still show a 27% rise to almost 9m by 2030.

| Year/scale | 1-2 | 3-5 | 6-8 | 9-10 | total |
|---|---|---|---|---|---|
| 2010 | 2.35 | 2.59 | 1.55 | 0.54 | 7.04 |
| 2020 | 2.65 | 2.94 | 1.72 | 0.59 | 7.90 |
| 2030 | 2.96 | 3.34 | 1.96 | 0.68 | 8.94 |

*Estimates of the number of adults in the UK with different levels of disability from age 20 between 2010 and 2030 (millions)*

Estimates for the number of whole time equivalent carers have been calculated using the scale proposed by Nuttal et al. The table below is based on a 40 hour week but if is assumed that the average number of hours per week caring is 20 hours, the implied number of engaged in caring activities doubles.

| Year/scale | 1-2 | 3-5 | 6-8 | 9-10 | total |
|---|---|---|---|---|---|
| 2010 | 0.29 | 0.97 | 1.17 | 0.61 | 3.04 |
| 2020 | 0.33 | 1.10 | 1.29 | 0.67 | 3.39 |
| 2030 | 0.37 | 1.25 | 1.47 | 0.76 | 3.85 |

*Estimates of the number of whole time equivalent carers between 2010 and 2030 (millions)*

Over two-thirds of adult social care jobs are in the independent sector. The private sector accounts for 46% of the total or 803,000 jobs, which is nearly twice as many as in the voluntary sector. In addition there are an estimated 197,000 adult social care jobs in councils, 73,000 in the NHS and 263,000 with recipients of direct payments. Around 38% of jobs are in domiciliary services, 36% in residential care, 17% in community services and 9% in day care services.

Data on unpaid care, the other part of the care equation, is more difficult to source. The 2001 Census for the first time included a question on family and friends who provide unpaid care. The question was: 'Do you look after or give any help or support to family members, friends or neighbours or others because of: long-term physical or mental ill-health or disability or problems related to old age?'

Based on this data and intervening population changes, Yeandle and Buckner (2011)[12] estimate that in England there are over 5.3m carers (6.4m in the UK), family, friends and neighbours who provide unpaid care to someone who is ill, frail or disabled. The care they provide to help sustain people in their own homes and in their own communities is estimated by the authors to be worth £96bn in England alone if replacement care assumed to be valued at £18 per hour.

The care provided is not full-time but covers a spectrum of ages including younger ages and ranges from a few hours per week to over 50 hours and so the number of whole time equivalent carers is substantially less than this figure. Also subsumed within this figure are likely to be recipients of Direct Payments, which are included in the Skills for Care figures above. In addition recent research by the same authors suggests that a high proportion of care assistants combined their professional work with unpaid care so there is some danger of double counting.

Whilst the Census is based on all households and therefore able to provide local data, it is now more than 10 years out of date. Interim data are available from surveys most notably the General Household Survey (GHS), but the most comprehensive of recent surveys is the Survey of Carers in Households - 2009/10 England, commissioned by the NHS.[13] This found that there were and estimated 5 million adult carers in England or around 12% of people aged 16 or over of whom 48% provided care for 20 hours or more per week.

In summary, the answer to the question of how many carers there are in the UK is not straightforward and needs careful definition depending on purpose for which a figure is needed. The analysis presented therefore needs to be seen in this light but the impression that numbers are substantial and increasing at a rapid rate is basically

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This scale in turn is based on work by Martin, J., Meltzer, H. & Elliot, D. (1988). OPCS surveys of disability in Great Britain, Report 1. The prevalence of disability among adults. London: HMSO. The report gives examples of peoples disabilities at different points on the scale. For example, category 1: a man aged 59, deaf in one ear; category 2 a woman aged 71 with angina and eye problems; category 6 a man aged 65 with arthritis in spine and legs, a slight stroke and heart condition.

[12] Valuing Carers 2011. 'Calculating the value of carers' support'. http://www.sociology.leeds.ac.uk/assets/files/research/circle/110512-circle-carers-uk-valuing-carers.pdf

[13] Survey of Carers in Households - 2009/10 England. Department of Health, 2010. www.ic.nhs.uk/pubs/carersurvey0910

correct. In a later section we show how care varies over the life cycle and how the intensity of care provided depends on wider considerations including family size.

**1.5 Affordability of long term care among the older population**

It is generally accepted that the younger population needing long term care will not have built up enough resources to be able to self fund and the state provides support in these cases. For the older population, where demand for long term care is set to increase, most people are expected to make a contribution but how that contribution is assessed and what the state provides has been the subject of intense debate.

Income in old age includes several possible components: an occupational pension, state pension and means tested benefits such as Pension Credit, Council Tax Benefit and Attendance Allowance, which is not dependent on income but only care needs. Some benefits are in kind such as subsidised housing, free public transport or membership of social clubs. Assets by contrast consist of savings, but the most significant component for most people is housing wealth.

Imagine it were possible to put all income and private wealth into a single pot in order to calculate the notional number of years of care that could be afforded based on the annual average cost of institutional care. Box 3 shows how this calculation can be made and how it is possible to split the older population into wealth bands ranging from A the lowest to E and higher.

The picture obtained is of considerable differences in ability to pay with the population resolving into essentially two groups: (a) either unable to pay for long term care for more than one year (20.7% of the total) in which case they are band A or (b) able to pay for care for more than 5 years (68.5%) in which case they are un-banded. The remaining 10.8% of the population is spread rather evenly between bands B and E.

Most of the differences in income and wealth are accounted for by access to a good pension or property ownership. Of the one third of the 65+ population with no property assets 79% fall into band A as compared with only 1% of those with property assets. Of the two thirds with property assets, 88% could notionally afford long term care for more than 5 years.

When this is disaggregated by gender, co-habitation status, education, health etc. the picture changes somewhat. For example, there are 26% more females than males in the 65+ age group. Of these 23.1% are in band A as compared with 17.4% of males; however, some of this difference is explained by the fact that females outlive males and have a lower net worth in old age.

Based on living arrangements, 31.1% of people living alone fall into Band A as compared with 13.1% of couple households. Of those with no educational qualifications 30.5% are in Band A as compared with only 10.7% of those with some educational qualifications. Differences in the ability to pay between those in good or poor health are much less because the survey captures people that incur poor health *after* they have accumulated their wealth.

The above analysis varies also by cohort. People born after 1950 have tended to benefit more from home ownership than people born before. Assuming the critical age for needing long term care is 85 the percentage of the population who fall into band A will fall from around 30% to 17% by 2025 so that in future years the proportion of people that will be notionally able to pay will be greater. Further

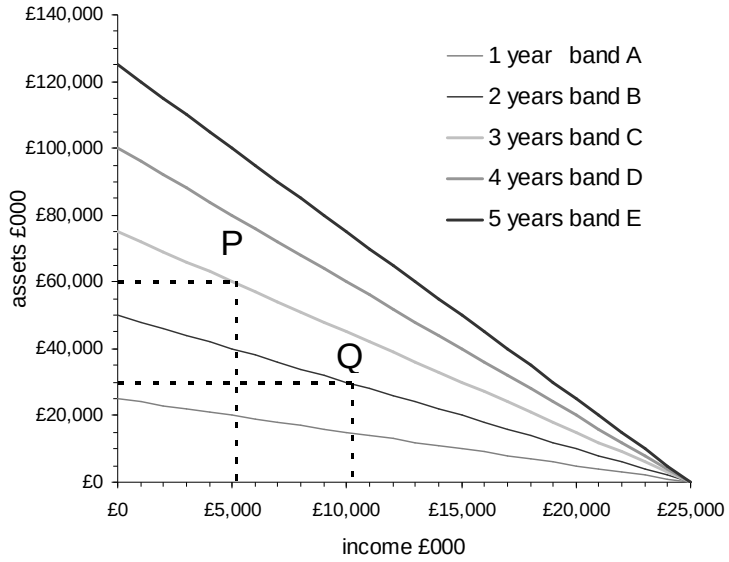
discussion and illustration of how wealth and income are distributed among the 65 and over population is at Annex C.

The distribution of income and assets in old age goes to the heart of the policy debate on how long term care should be funded in future. The present system, summarised in the next section, is sustained by a complex funding system consisting of universal benefits, private income, and means testing. Despite the contribution of personal finance to funding, the small penetration of affordable private sector insurance and other financial products is considered anomalous but is a partial consequence of the complexity of the system.

In summary, unless more resources can be unlocked and without changes in the wider system for support and care, it is likely that families and friends will be increasingly required to fill the care gap. This outcome will be the inevitable result of changes in society including the rising demand for care coupled with slower economic growth, increases in pension age and stricter benefit rules, but also extremely tight social care budgets. If unresolved, this has the potential to worsen the position of carers relative to others in the economy who do not have caring responsibilities themselves.

In section 2, we review the system for funding care, the contribution of households and carers to economic output and how they can be supported financially both to care and to earn a living. In section 3, we consider the changing structure of families and analyse the care life cycle from cradle to grave both from the point of view of care giving and care receiving. In particular, we analyse the phenomenon of 'sandwich' or pivot generations.

In section 4, we pull these different strands together. It is argued that a key aim of the care sector must be to increase productivity and so new ways are explored for improving care delivery and efficiency. It is argued that productivity can be improved by reducing what is required e.g. through health improvements or earlier intervention; making resources go further through increases in efficiency; or by a more intelligent use of resources.




**Box 3: Affordability of long term care**

Suppose that institutional care costs are £25,000 per annum. A person with £60k of assets and £5k annual income would be notionally able to afford three years worth of care from their own resources [£60,000/(£25,000-£5000) = 3 years]. See point P in Figure above.

A person with assets of £30k and an income of £10k would be notionally able to afford up to 2 years worth of care from their own resources [£30,000/(£25,000-£10000)= 2 years]. See point Q. It follows that any person with an income greater than £25k is self funding on this basis. This information can be used to place people into 'wealth bands' based on which entitlement to state support could be assessed and financial support provided on a sliding scale.

For example Band A equates to people that can notionally afford care for 1 year, B 2years….band E 5years. It follows that people banded above E are notionally self-funding.

The distribution of wealth in the 65+ population is set out in the following table, based on ELSA (the English Longitudinal Survey of ageing).

| Wealth band | 65-74 | 75-79 | 80-84 | 85+ | Total | as % of population 65+ |
|---|---|---|---|---|---|---|
| A | 722 | 354 | 336 | 362 | 1,774 | 20.7 |
| B | 93 | 27 | 40 | 28 | 188 | 2.2 |
| C | 87 | 48 | 43 | 31 | 210 | 2.4 |
| D | 144 | 45 | 45 | 36 | 270 | 3.1 |
| E | 153 | 45 | 29 | 34 | 260 | 3.0 |
| unbanded | 3,284 | 1,148 | 758 | 693 | 5,882 | 68.5 |
| Total | 4,483 | 1,667 | 1,251 | 1,183 | 8,584 | 100 |

*Estimates of the numbers of people by wealth band in 2010 based on ELSA ('000s)*

# 2. Paying for care

## 2.1 Introduction

The economics of caring are complicated by the multiplicity of ways care is provided, because of differences in definitions of care and because of statistical gaps. In general terms, care is typically characterised according to the person being cared for, the source of care, the quantum of resource provided, the type of service (whether health or social care), or the setting where care is provided (home, hospital institution, day centre etc.).

Countries have different requirements for, and ways of working with carers. For example, Germany provides cash payments to incentivise care providers, whereas England and Japan tend to provide services in kind to support the families of disabled people, although this is changing somewhat. In general, funded care fills gaps in unpaid care and vice versa depending on individual circumstances and so movements in the boundary between paid and unpaid care are important from several perspectives.

Current methods of accounting for economic output ignore the value of unpaid care for the purposes of measuring GDP, so that a shift from paid to unpaid care will reduce GDP assuming that total demand for care is unaltered. It can be argued that its inclusion would enable better evaluation of strategic alternatives for shifting the boundary in directions that improve outcomes for carers but also make a positive contribution to GDP.

Because it is unclear how this mechanism works, we consider this among several issues relating to financial support for carers who are considering a return to work. Using a hypothetical worked example, we analyse the financial consequences of the decision to work on a carer's personal finances on the impact on replacement care and GDP.

Following a brief description of how the present system works and is funded, we introduce the hypothetical concept of a 'Care Credit' which provides financial help for people that wish to balance care with work and contrast it with the present system based on Carer's Allowance. We conclude that it should be possible to reposition financial support for carers in a way that helps them to work if they want to but also recognises their contribution to the care economy in GDP terms.

## 2.2 The present system of financing care

There are different systems for the publicly funded element of care and support operating in Scotland, Wales, England and Northern Ireland and differences also in the application of the systems at a local level, making the UK system of social care administratively complicated and hard to understand.

Figure 1 shows the three main financial streams that pay for care: A) public funding based on grants financed out of taxes; B) out of pocket payments and social security payments that are used to procure care privately; and C) unpaid care provided by family and friends for which costs are measured chiefly as opportunity costs such as foregone earnings.

Resources are channelled through Local Authorities (P) who assess individuals needs and source care on their behalf (S), or they are procured directly by

individuals on a private basis (Q) (for example, when a family places an older relative in residential care) or it is the family or friends that provide care to the end user (T). However, these systems are not mutually exclusive and care pathways may combine all of these channels at some point in the care cycle.

Under the current system, local authorities with social services responsibilities commission social care services on behalf the local community. Each local authority carries out an assessment of need to determine the level and type of disability and care needs of an individual. A means test is used to determine the level of financial entitlement and any personal contribution to the cost of care although it does not apply in all cases or areas (e.g. in the case of personal care).

Social care is a significant proportion of local authority spending but it is not ring-fenced by central government. Due to current funding pressures, it is the case that only the people that have the highest needs and lowest means that tend to receive any financial help. Furthermore, because spending is discretionary, it means that different eligibility criteria apply in different areas leading to what has been term a 'postcode lottery'.

Apart from local authorities, the NHS provides a small number of free 'continuing care' places to those who meet the stringent criteria laid down either in an institutional setting or at home. The availability of continuing care places is a source of tension in the system because the financial consequences of being assessed ineligible for NHS Continuing Health Care can be very significant for individuals who would have to fund the care themselves.

Estimates of the total value of adult social care are complicated by the mix of funding sources, provider organisations, definitional issues, data sources and geography - notably whether just England or the whole UK.[14] According to the Commission for the Funding of Care and Suppport, net public sector expenditure on adult social care in England in 2009/10 was £14bn of which £6.5bn was spent on adults age 18-64 and £7.5bn was on older people. However this does not include private expenditure on older people estimated to be worth £8.3bn a year.[15]

In addition to the above, non-means tested financial support is separately provided through the social security system in the form of disability benefits (Attendance Allowance and Disability Living Allowance[16]), which provide a measure of flexibility and choice over covering the costs of disability. In 2009/10 combined expenditure on the care component of Disability Living Allowance and on Attendance Allowance was £11.7bn.

This gives a total of £34.0bn for care and support, but notably excludes expenditure elsewhere in the UK or the value of unpaid care through channel (C) in Figure 1. Buckner and Yeandle (2011) estimate for example that the replacement value of unpaid care for the whole UK is £119bn a year or three and a half times more.[17]

[14] Karlsson M., L. Mayhew, R. Plumb, R. and B. Rickayzen (2006a). 'Future cost for long term care: cost projections for long term care for older people in the United Kingdom'. Health Policy, vol. 75, 187–213.

[15] Fairer Care Funding: Analysis and evidence supporting the recommendations of the Commission on Funding of Care and Support Figure 1.2.Source: The Report of the Commission on Funding of Care and Support, July 2011

[16] Other means of financial support is channelled through benefits such as Pension Credit, Council Tax and Housing Benefit.

[17] 'Valuing Carers 2011: Calculating the value of carers' support '. Published by Carers UK, London. ISBN 978-1-873747-02-5

Limited financial support is also available through Carer's Allowance worth about £1.5bn a year (or 1% of the welfare budget), which is paid to adults who earn less than £100 a week and spend 35 hours or more caring.

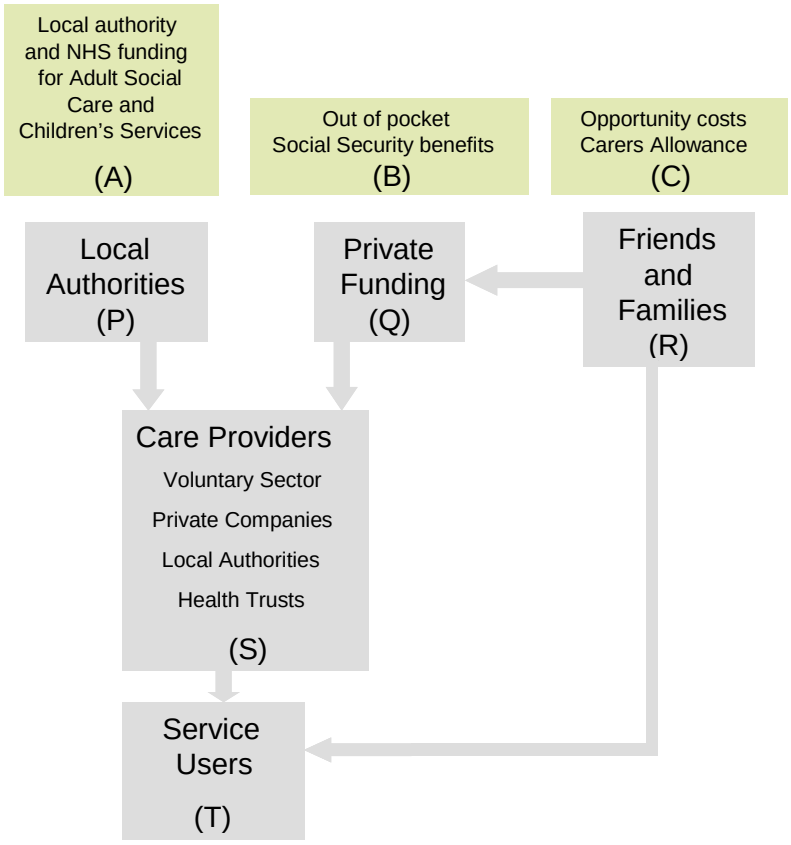



*Figure 1: Flow diagram showing sources and uses of resources in the care system.*

Although they only control a proportion of expenditure, local authorities play a pivotal role in distributing public funds for social care. Since 1996, people eligible for social care support have had the option to take a cash payment to purchase the support they need under the 'Direct Payments' system which is designed to encourage and promote choice and control over the sources and types of care .[18] Direct Payments are part of the 'personalisation' agenda which has the potential to change the way care is provided.

Direct Payments are also available to people who have been assessed as needing support in their caring role, to buy services from an organisation or to employ somebody directly. While Direct Payments only use money from a local authority social care budget, the more recent introduction of individual budgets or 'personal budgets', extend this principle by provide maximum control and choice how the money is spent.[19]

Depending on how the rules are framed and evolve, personal budgets are likely to exert a considerable long term impact on the organisation of care and support and

[18] For further information see: Social Care Institute for Excellence (SCIE) research briefing 20: The implementation of individual budget schemes in adult social care

[19] The Individual Budgets Pilot Projects: Impact and Outcomes for Carers. Glendinning et al, Working Paper No 2298, Social Policy Research Unit, University of York, and PSSRU, University of Kent. www.york.ac.uk/inst/spru/research/pdf/IBSENCarersRep.pdf

introduce and element of competition and flexibility among providers whether close associates or family, or providers from the voluntary, private or statutory sectors. According to the Association of Directors of Adult Social Services, there are already over 340,000 eligible users and carers using personal budgets presently or 35% of the total caseload.

As the state withdraws from many areas, it is carers that will need to take up the slack. But, better support and help may assist them in doing so. Increases in pension age, only modest growth in social care, as well as the ageing population will draw more people into care. As we have seen, the demographics of caring will also change as the age spectrum for carers becomes more stretched.

The private sector could also be of assistance in this regard. There are insurance products for people who fall ill or lose their jobs but none, apparently, for carers who leave their jobs to care for someone. The issues are different, admittedly, and would need careful consideration, but a policy that is triggered by a care assessment reaching a certain care threshold for named individuals (for example, elderly parents) is worthy of consideration.

### 2.3 A simplified view of the social care economy

As noted, services provided by members of households or families to each other free of charge are not counted in GDP, the main measure of economic output, because no money is transacted. So if a person marries his or her own care worker for example, reported GDP may actually go down. Because of these anomalies, economic theory has struggled to grasp the important economic role played by unpaid carers.

Eisler (2007)[20] examined economies through a wider lens in which care giving is both at the heart of society but also the economy. In this model, households are a fundamental economic unit in which the main outputs of which are human and social capital (see Figure 2). Households are sustained through work, social security transfers and support in kind from families and friends.

Economists are still coming to terms with basic activities such as preparing meals, cleaning, and washing all of which are overlooked in the national accounts of economic activity. Statistics Finland for example found that GDP is increased by 40% and household consumption by 60% when household production is included in the national accounts but they do not distinguish explicitly care and support for disabled household members.

It is within this context that we construct a simplified care economy that consists of either paid or unpaid care or both. In Figure 3(i), all care is unpaid care provided either in a family or community setting. Some financial support is provided through the social security system as income replacement for carers. No cash is exchanged other than social security payments and so that the value of care does not count towards GDP.

[20] Eisler, R., (2007). The Real Wealth of Nations. San Francisco: Berrett-Koehler publishers, San Francisco

In Figure 3(ii), a mixed care economy, there is both unpaid care and paid care (A and B) in which paid care is provided by care professionals. There is dual support from the state in the form of financial assistance through the security system and through benefits in kind. These benefits might be directly supplied services that are owned and operated by the state or indirect services paid for by the state but supplied by others.

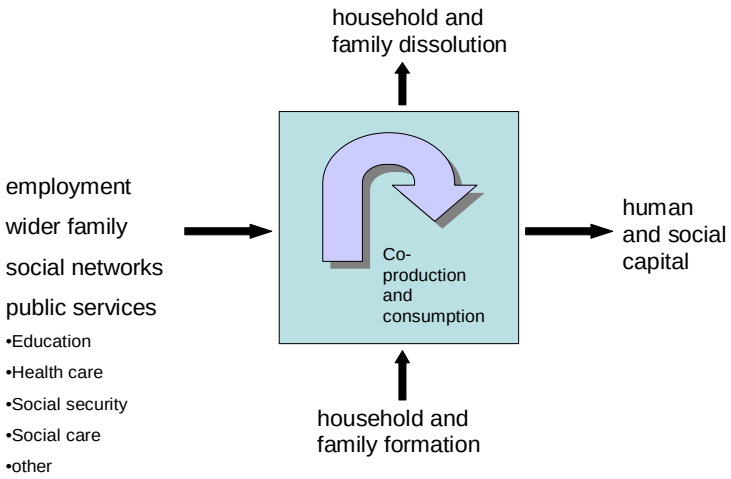



*Figure 2: The household as an economic unit of production*

In Figure 3(iii), a wholly formalised care economy, all care is provided by professional care workers who receive a normal wage. Since this form of care economy is a wholly cash economy the wages earned by professional care workers count towards GDP and the state derives tax revenues from the wages of professional care workers.

The decision to work or to care is driven by many factors only one of which is financial motivation. There are opportunity costs that arise from lost leisure time or time spent on other activities such as education, shopping and so forth. These kinds of costs will impact differently depending on the carer and their attitudes towards caring.

If the costs of paid-for care were to increase relative to wages, the most likely response would be an increase in unpaid care. This relationship is not a linear one since some unpaid carers are themselves unable to compete effectively in the labour market because of health, educational attainment or age. The willingness to do work is also affected by the altruistic nature and/or emotional bond of many unpaid caring relationships.

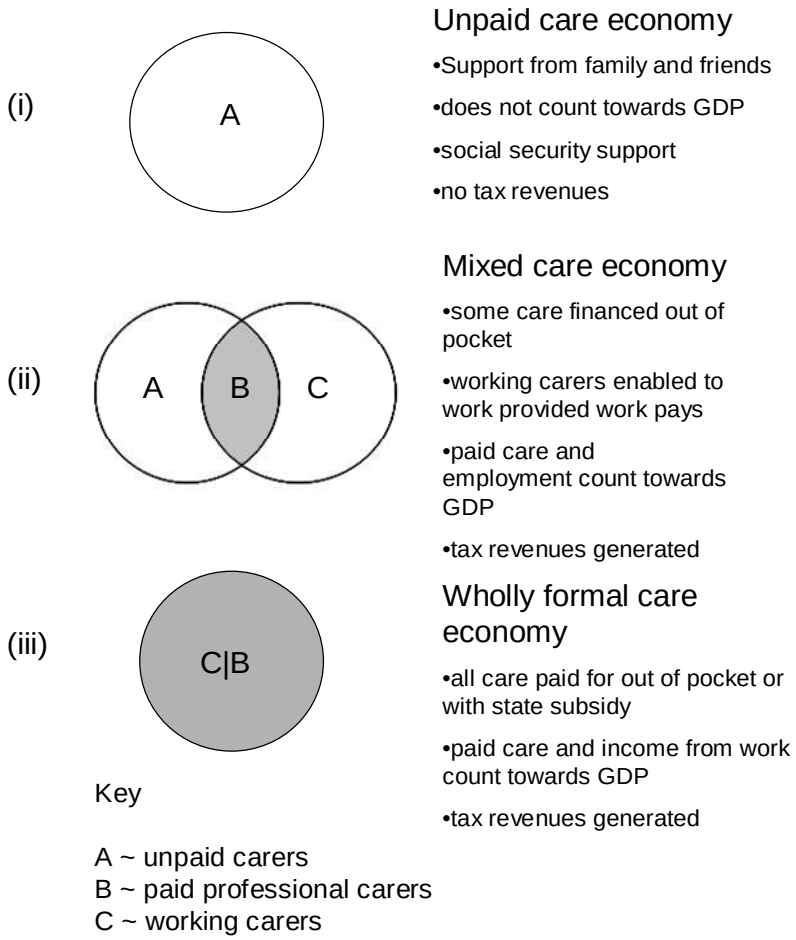



*Figure 3: Some features of a simplified care economy*

**2.4 The case for financial support for carers**

There are different ways of supporting carers either in kind or in cash through Direct Payments, an allowance or benefit, tax relief or credits. Direct Payments differ because they are a form of wage to pay for services rendered and so are not the same as a cash benefit. If the policy objective is to help more carers into work or combine caring with work then each approach is likely to be more or less effective in achieving this aim.

Carer's Allowance, currently the main benefit for carers, was originally conceived as income replacement for people caring 35 hours or more a week (i.e. 87.5% of a 40-hour working week). At £58.45 per week (2012/13 rates) it is hardly an adequate income replacement given average wage levels although it may be combined with other benefits and rules allow up £100 a week of additional earnings after deductions.

However, it can be argued that the cliff edge nature of the benefit and the complex entitlement rules are not conducive to combining work and caring roles if this is to be the policy objective. According to the 2009/10 Survey of Carers in Households,[21] respondents said that flexibility was the most important thing that would help carers to take up paid employment.

[21] www.ic.nhs.uk/pubs/carersurvey0910

In considering the alternatives, it is helpful to illustrate an alternative approach by way of a hypothetical example using some assumed but arguably realistic figures as figures as illustration. To make the comparison more realistic, we assign a notional value to unpaid care in GDP terms so as to fully assess the implications for economic output as the boundary shifts.

To assist with the illustration, we introduce a hypothetical new taxable allowance which, for the sake of argument, we will call 'Care Credit' and which we then compare with Carer's Allowance.[22] It is based on the example of someone who needs intensive care at home and constant attendance although the carer does not necessarily live in. Table 1 considers the case of whether a carer would be better off not working; working part time or working full time.

For illustration, we assume average wage is £15 per hour as compared with an assumed going rate of £8 per hour for the cost of paid care. The table shows how the decision on whether to work or care would impact on a carer's income before and after care costs are taken into account. Care Credit is assumed for illustration to be worth up to £100 a week but is gradually withdrawn in proportion to the number of hours worked per week.

| | Category | A | B | C | D |
|---|---|---|---|---|---|
| 1 | Income from employment | 0.0 | 15.6 | 23.4 | 31.2 |
| 2 | Notional value of unpaid care | 16.6 | 8.3 | 4.2 | 0.0 |
| 3 | Cost of replacement care | 0.0 | 8.3 | 12.5 | 16.6 |
| 4 | Care Credit | 5.2 | 2.6 | 1.3 | 0.0 |
| | | | | | |
| (i) | Income after tax excluding care costs (row 1 less 20% tax) | 0.0 | 12.5 | 18.7 | 25.0 |
| (ii) | Income after tax and care costs (i) - row 3 | 0.0 | 4.2 | 6.2 | 8.3 |
| (iii) | Income plus Care Credit after tax (row 1 + row 4 less 20%) | 4.2 | 14.6 | 19.8 | 25.0 |
| (iv) | Carer income plus Care Credit after tax and care costs (iii) less row 3 | 4.2 | 6.2 | 7.3 | 8.3 |
| (vi) | Impact on public expenditure (Care Credit less tax revenue) | 4.2 | -1.0 | -3.6 | -6.2 |
| (vii) | Impact on GDP (1+ 3) | 0.0 | 23.9 | 35.9 | 47.8 |
| (viii) | Impact on GDP including value of unpaid care (1+2+3) | 16.6 | 32.2 | 40.0 | 47.8 |

*Table 1: All figures in £000's per year for an individual based on 52 week year*

**Key to Table 1:**

A - Full time unpaid carer at 40 hours per week
B - Carer works 20 hours a week, cares for 20 hours and pays for 20 hours care
C - Carer works for 30 hours a week, cares for 10 hours and pays for 30 hours care
D - Carer works for 40 hours a week, cares for 0 hours and pays for 40 hours care

*Assumptions*: £15 per hour employed wage with no other income; £8 per hour paid and notional care wage; Carer's credit £100 per week pro-rated based on hours of care provided; assumed average tax rate 20%.

The example given is based on a carer who increases their weekly working hours in steps from zero (A), 20 hours (B), 30 hours (C) and 40 hours (D). The rows show the

[22] Care Credit does not currently exist and is invented for illustration. A properly formulated Care Credit would need to sit along side and be complementary to the rest of the benefits system, which is currently being reformed.

resultant changes in income, the notional value of the unpaid care provided the cost of replacement care, and the changing value of Care Credit that would result. The lower table shows the impact on a carer's income before and after tax assumed to be 20% with and without Care Credit and also the consequential replacement care costs.

The lower table shows how the decision to work would impact on GDP and public expenditure through the tax and Care Credit system (rows (vi) to (viii)). Our accounting system shows that real GDP increases if a carer does paid work because of their contribution plus the value of replacement care. In this case, if the carer works full time, the addition to GDP is £47.8k and comprises of the carer's income of £31.2k and that of the paid care worker which is worth £16.6k (see rows 1 and 3 and (vii)).

If the carer does not work, then there is no impact on GDP but the notional value of output of a full time unpaid carer is worth £16.6k worth assuming it is priced at the same rate as paid care. As a carer extends their weekly of hours of work, the contribution to GDP increases and the notional contribution decreases. Once the carer is in full time work the notional contribution shrinks to zero as may be seen by comparing lines (vii) and (viii).

Comparing rows (i) and (ii) shows the significant impact of care costs on income after tax and why a carer must have a reasonable hourly wage in order to make work pay. Rows (iii) and (iv) shows the improvement in net income as a result of Care Credit after tax and replacement care costs are netted off. With these wage parameters, it is financially advantageous to work if the carer does not pay for care but less so otherwise.

The financial advantage is hence greater the higher income is compared with the cost of care. In this example, a carer would have to earn £10 an hour just to break even since after tax this would only be worth £8, in other words the same as the cost of paid care per hour. In addition, it will depend on the rate of withdrawal of Care Credit relative to the number of hours worked; thus a high withdrawal rate could mean that a carer could actually be worse off the more hours they work.

In terms of public finances, the case for Care Credit then depends on the extra numbers of carers that would be prepared to trade care for work for each additional £1 of Care Credit versus the cost of replacement care. The lower table shows that based on these assumptions there would be a net saving to the exchequer as tax revenue would outweigh the cost of Care Credit and GDP would increase, but it would depend on the appropriate work incentives and supply of suitable jobs.

The above is for illustration only and designed to show the value of care to the economy and the theoretical income and public expenditure benefits of a Care Credit approach to helping carers meet the cots of care whilst working. However, a full analysis would need to take into account other factors including interactions with other areas of the current tax and benefit system. Since the benefits system is currently being reformed and full details of these reforms are not yet known these arguments must remain theoretical.

### 2.5 Carer's Allowance

We can contrast the above approach in general terms with the system for providing financial help through the social security benefits system based on Carer's Allowance. This is a tightly defined and targeted benefit based on the narrow

definition of care and even narrower definition of what qualifies for financial support. It differs from the concept of a 'Care Credit' above because it is essentially only paid to people on little or no earnings.

To be eligible a carer must look after someone receiving a qualifying disability benefit such as Disability Living Allowance middle or higher rate care component or Attendance Allowance, and provide at least 35 hours of care a week. In addition the carer must be aged 16 or over, not in full-time education, earn less than £100 a week after deductions, and be the sole carer of a person. The current value of the benefit is £58.45 a week – 2012/13 rates (further details of how it works are given at Annex B).

If two or more people share the care of one person, it is necessary to decide who will be the main carer in order to receive the allowance. If both the carers of the person being cared for are also caring for someone else, both can claim Carer's Allowance as long as all the criteria are met. Consideration would need to be given as to whether this principle would be extended to a Care Credit system. Currently, about 83% of carers look after one person only and 17% to two or more.

People who fulfil the eligibility criteria may not be entitled Carer's Allowance if they receive other earnings replacement benefits such as the State Pension or Employment and Support Allowance, for example. These are known as 'overlapping benefits' and the principle is that individuals cannot be compensated twice for the same lack of full time paid work. Because the State Pension is the main overlapping benefit, most people paid Carer's Allowance are under pension age.

Bertaud[23] has estimated that the total number of people receiving Carer's Allowance or with underlying entitlement is 940k or less than one sixth of the estimated number of care providers in the UK.[24] Of these, 432k or 46% receive payment and 508k or 55% do not. Of the 46% receiving payment 373k are under pension age and of the 55% that only have entitlement (i.e. receive no payment) an estimated 478k or 94% are over pension age (see Table 2).

| Category | Under pension age | Over pension age | total |
|---|---|---|---|
| Carer's Allowance in payment | 373 | 59 | 432 |
| Underlying entitlement | 30 | 478 | 508 |
| total | 403 | 537 | 940 |

*Table 2: Carer's Allowance and underlying entitlement to Carer's Allowance (000s) people). Source Bertaud, 2010.*

Box 4 provides basic details on the number, age and durations on benefits of people that receive Carer's Allowance. The charts show a steady rise in numbers peaking at age 40-44 before levelling and then falling sharply after age 59 after which the State Pension, the main replacement benefit kicks in. We observe that women receive Carer's Allowance much more often than men but their number peaks at an earlier age, whilst the number of men increases with age until their pension age is reached at 65.

Around 40% of those getting Carer's Allowance have average benefit durations of over five years. For example, a second chart (the area denoted A in chart (ii)) shows

[23] The take-up of Carer's Allowance: A feasibility study. Richard Berthoud, Department for Work and Pensions. Working Paper No 84 (2010)
[24] The equivalent figure in the 2009/10 survey of carers was 11%.

a core of carers aged between 50 and 55 that have been in receipt of Carer's Allowance for an estimated 8 years or more. This chart is created by plotting the average duration in years of each recipient of Carer's Allowance against their age with each contour corresponding to the number of claimants.

**2.6 A comparison of options**

The contrast between Carer's Allowance and the concept of Care Credit can now be clarified. Carer's Allowance is essentially a very small benefit designed to provide financial assistance to carers that cannot work or only work in a limited capacity (up to a maximum of £100 in income per week after deductions), whereas as Care Credit would pay out in proportion to the number of hours spent working and caring.

Table 3 compares a carer on Care Credit (I) with someone on Carer's Allowance (II) who earns up to the maximum regardless of the number of hours spent caring (A to D) For illustrative purposes, we assume that employment pays £15 per hour, the same as before and that Care Credit is worth a maximum of £100 per week. An average tax rate of 20% is also assumed as before whilst the person on Carer's Allowance pays no tax because they are below threshold for paying tax.

The maximum a person on Carer's Allowance can earn before the benefit is withdrawn is just over £8k per year (52 x (£58.45+£100) = £8,239.40), whereas there is no limit for a person on Care Credit. In terms of net public expenditure (tax minus benefit costs), a person on Carer's Allowance generates no tax revenues because their income is too low but the person on Care Credit is potentially a net contributor to public expenditure depending on how many hours a week they work.

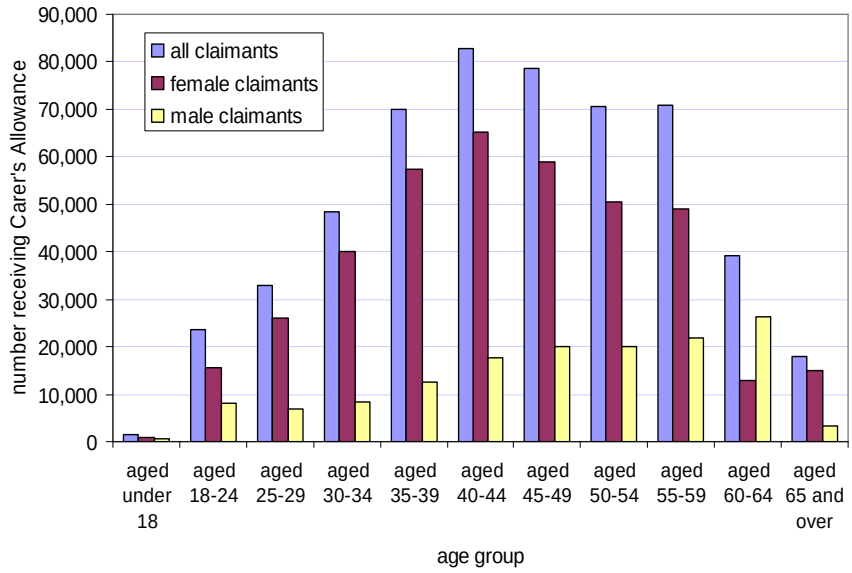
| | Category | A | B | C | D |
|---|---|---|---|---|---|
| I | Carer income before tax including Care Credit | 5.2 | 18.2 | 24.7 | 31.2 |
| II | Carer income based on Carer's Allowance + up to £100 a week | 8.1 | 8.1 | 8.1 | 5.2 |
| I | Cost of Care Credit | 5.2 | 2.6 | 1.3 | 0.0 |
| II | Cost of Carer's Allowance | 2.9 | 2.9 | 2.9 | 0.0 |
| I | Tax revenue @20% (row I X 0.2) | 1.0 | 3.6 | 4.9 | 6.2 |
| II | Tax revenue @20% | 0 | 0 | 0 | 0 |
| I | Net impact on public expenditure of Care Credit | 4.2 | -1.0 | -3.6 | -6.2 |
| II | Impact on public expenditure assuming Carer's Allowance | 2.9 | 2.9 | 2.9 | 0.0 |
| | Difference | 1.3 | -3.9 | -6.5 | -6.2 |

*Table 3: Comparison of wages and net public expenditure based on Care Credit and Carer's Allowance for a hypothetical carer (£000s)*

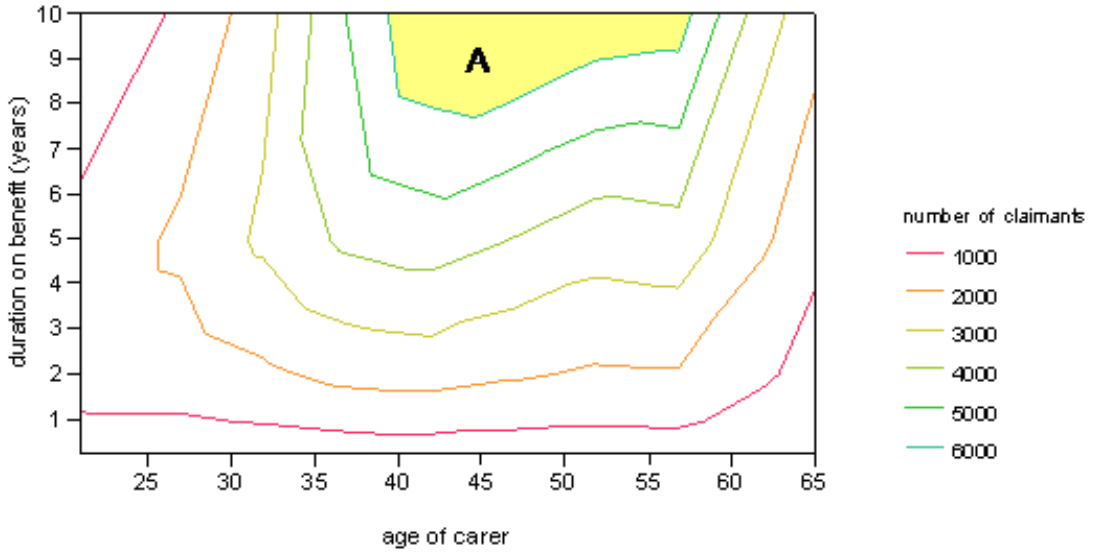
To summarise, the problem with Carer's Allowance is that there is an income 'cliff edge'. Someone that is earning £100 a week and receiving Carer's Allowance at £58.45 a week (2012/13 rates) would need to earn more than £158.45 after expenses to make working longer hours financially pay. A Care Credit system would boost the earnings of part-time workers, and provide the scope to work longer hours if desired but the cost in public expenditure terms would only pay off if sufficient people worked.

On the other hand, it can be argued that in a less restrictive system of financial support with no cap on earnings or hours of care provided, a carer would have greater flexibility to take a job that suited their experience and qualifications and be able to choose the hours that are able and willing to care for. This would have the

benefit of reducing net public expenditure and increasing GDP by more than GDP is increased under the present system.




(i)




(ii)

**Box 4: Recipients of Carer's Allowance**

Figure (i) shows that Carer's Allowance is highest between ages 35 to 59 and peaks between age 40 and 44. There are many more female than male claimants who tend to rise in number with age.

Figure (ii) is a contour plot in which contours represent numbers of claimants by age and benefit duration. It shows a concentration of people aged 40 to 55 (A), some of whom will have had entitlement for 8 years or more of their lives.

# 3. Profiling carers, families and households

## 3.1 Background

A person's relationship with their families is probably the most important thing in their lives. Most people want to, and would be able to care for their parents just as their parents cared for them as they grew up, although this is not a legal requirement as is caring for children. Providing care and support helps to bond families and communities together and creates social capital which can lead to wider benefits e.g. better health, educational achievement, economic growth and lower crime.

Being a carer or being cared for by a relative may be seen as a right as well as duty but also for some people it is a choice or a necessity.[25] Much unpaid care is reciprocal and relational in nature and can be regarded as a 'gift' between generations or between friends, in which the benefits of care-giving go beyond the actual service and include admiration, and social approval. Thus social capital may take on even more value in the present economy in which many family members find themselves working in less stable environments.

However, whilst roles and responsibilities as well as duties of care may be mutually reinforcing and are therefore an important from a policy perspective, families need sufficient income for care to be sustainable but their economic resilience may be challenged in a number of ways, most obviously through unemployment or other factors such as having a disabled child or an elderly parent at home.

In this chapter, we consider the effects of family structures on caring according both to the broad and narrow definitions of care. Using a purpose-developed model, we investigate the availability of carers over the life cycle among different types of families. As individuals live ever longer will they eventually run out of carers, but to what extent does it depend on family size and structure, intervals between birth years and other factors?

Because of the demographic tendency towards later births, care is becoming increasingly concentrated in certain phases of the life cycle, so that for example a parent may experience a simultaneous need to look after not only children but also ageing parents or even a disabled child or spouse. Using a different model, we investigate the he phenomenon of the so called 'sandwich' or 'pivot generation'.[26]
We consider the kind of family structures in which this possibility is more likely to occur and the potential duration of overlapping care phases in the life of a carer.

The demand for care would not be such an issue for society if more people stayed healthier for longer. The English Longitudinal Study of Ageing (ELSA) is a data resource on health, economic position and quality of life as people age. The survey covers a broad set of topics including health, disability, and healthy life expectancy; the relationship between economic position and both physical and cognitive health; and the nature of social networks, support and participation.

Our interest lies in understanding the relationship between caring and employment and the influences and patterns that arise. We find that economic activity among

[25] In many respects this is the same range of possibilities as for paid work and the analysis which follows also parallels the questions about the (paid) labour market.
[26] See for example Mooney, A and J. Statham with A. Simon (2002) 'The pivot generation: Informal care and work after fifty'. Bristol: Policy Press

people in their 50s is influenced by personal characteristics such as their own personal health, their level of education and gender, and the need to care for others. It turns out that being in good health is the strongest predictive factor, but having no caring responsibilities, a good education and being home owner are also very important.

A problem with most attempts to improve the care system at the local level is the lack of local data that could underpin and direct local caring strategies since the data that are available are unsuitable, incomplete or out of date. However, much useful data is locked up in administrative systems which could be exploited for much greater benefit. To illustrate how this could work, we use data for a medium sized English local authority to show general patterns in household size and demography.

Questions that may be asked of the data include whether older households are worse off than younger households, what difference to income it makes to have children of pre-school rather than post school age or a mix or both, what is the effect of having large numbers of children, single parenthood etc.? It is the framework that is important, because it provides the platform for linking other data sources to identify unmet need and patterns of caring.

### 3.2 Changes in the availability of carers over the life cycle

Over the long term, we find that that completed family size of cohorts of women born in ten year intervals since 1921 does not show large variation. However, by 1961 the number of women having no children had increased to 19% compared with 14.4% of women born in 1951. Whereas the frequency of women having 3 or 4+ children is largely unchanged, those bearing only 2 children have declined slightly as a proportion.

The latest data show that completed family sizes are recovering to previous levels and so concerns about a long term decline in numbers of children per family seem premature. Total fertility rates are now higher than they have been for some years, although there is also a strong trend towards later motherhood. For example, the average age at which women give birth is now 29 years having increased steadily since 1970 when it was about 26 years.[27]

Fertility is notoriously difficult to predict but it is reasonable to speculate that increases in income, child policies and changes to the tax system have contributed in some way to the changes seen. Also this period coincides with large rises in immigration with non-UK born women having generally higher fertility rates. The consequence of these trends is mainly that child birth today appears to be concentrating more and more around the later 20s and early 30s.

In the first model, we consider the availability of carers to an individual over his or her life cycle by considering it within the context of different family structures. In their lives an individual can call upon various close members of the family to provide care, so that at the youngest age it is obviously parents who are the main carers. In later stages of life however the picture is less clear, since it depends on the number and age of surviving members in the care pool and their health and other factors.

A key question is whether increasing longevity is likely to affect this availability at older ages and to what extent this depends on family structure. Crucial factors

[27] Marriage is less common than it once was but average age at which women get married is now over 30.

include age at marriage or partnership, birth dates and age gaps between children, partnership dissolution if it occurs and so on. To keep it manageable our examples only include parents, siblings and children as main carers.

The 2009/10 Survey of Carers in Households, for example, found that carers are most likely to be looking after close family member such as a parent (33%), a spouse or partner (26%) or a child (13%). Only 9% said that the main cared for person was a friend or neighbour. The most common reasons why care was required were physical disability (58%), a long standing illness (37%) or a sight or hearing loss (20%).

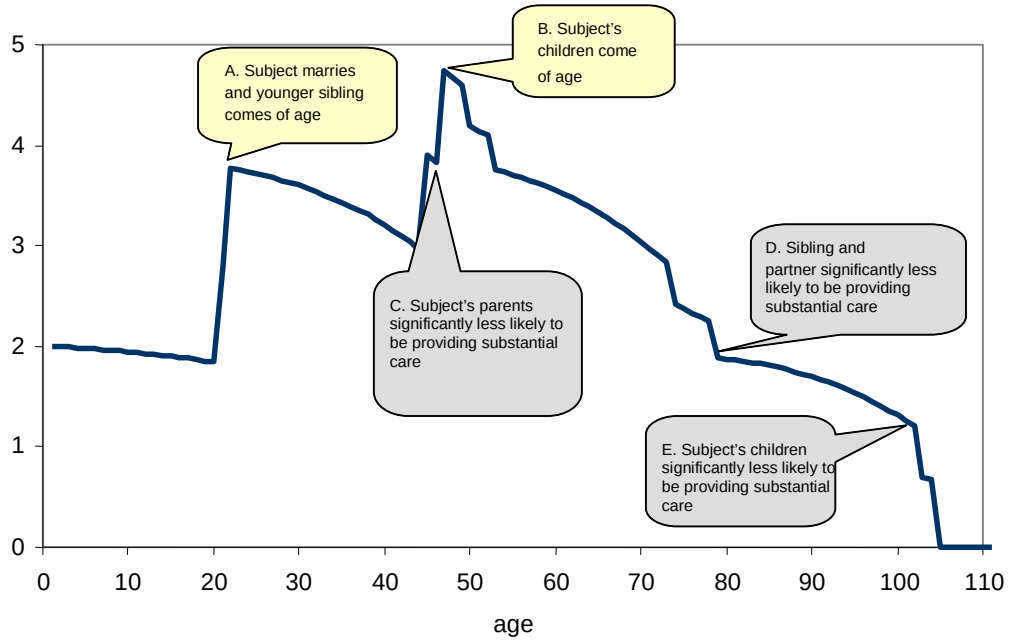
To make the analysis more realistic, male and female life tables by year of birth are used to age individuals in the model so that as each member ages the probability of death rises, so gradually reducing the size of the care pool. The maximum age to be at which the carer in the model is assumed to be providing very substantial care to be 75 and the minimum age to be a carer providing substantial care is 18, but these assumptions in the model can be varied. These ages are used for modelling purposes only as we know that people provide substantial care outside of these ages.

Box 5 shows an example of how it works and in particular how the size of pool is driven by life events such as marriage, child birth and attainment of certain ages such as 18 or 75 in this case. During an assumed life time of 100 years the average number of carers in this example ranges between 2.5 and 3 persons and can be regarded as a fairly typical case.

Importantly, the results show that average availability should not be affected by increases longevity except in the last years of life as long as each member is benefitting from the same rises in longevity as the previous generation. However, at the oldest ages (in this case 95+) the availability of family carers is depleted, as sons and daughters themselves older with their own conditions and less likely to be able to provide substantial care.

Other general findings are (for further examples see Annex A):

- The availability of carers is driven by life events including birth, deaths and marriage but also the timing of these events in relation to each other
- The longevity of individuals within the family pool and changes to longevity between generations are complementary
- Extreme longevity is an issue because other family members even of the next generation become more likely to have their own chronic conditions which make them less likely to be able to provide certain types of substantial care.




**Box 5: Carer availability over the life cycle**

For their care individuals usually rely on their immediate family. However, the size of the family care pool varies throughout the life cycle depending on birth dates, partnering and longevity (family members are aged using life tables dependent on birth year).

This chart is for a woman born to a two parent family who has one slightly younger sibling and no surviving grandparents. It shows the availability of care measured by the number of surviving family members over the life cycle. For simplicity it is assumed that the woman is able to provide care between the ages of 18 and 75 (these ages can be varied in the model).

A. She marries at age 21 as her sibling reaches 18. Her care pool increases to just under 4 including her new partner. It is not exactly 4 because there is a small probability that either of her parents may have died by that age.

B. She then has two children who turn 18 when she is in her 40s. This is the time in her life when carer availability is probabilistically highest, around 4.6 in this example.

C. Within a few years at around age 50 her parents turn 75 and are deemed less likely to provide substantial amounts of certain types of care. The number of carers falls from its peak to around 3 and then declines gently until she reaches age 70.

D. During her 70s both her partner and sibling are also deemed less likely to provide substantial amounts of care, which just leaves her children.

E. If she lives to age 100, she reaches a threshold when her children themselves develop their own conditions and become less likely to be able to provide substantial care leaving no family carers remaining (unless one counts grandchildren who are not included in this family pool).

- Individuals with the lowest life time availability of carers are those without either a long term partner or any children of their own [28]

- Women who partner older men will have a lower life time average number of carers

- Life time events such as divorce and remarrying should not have as great an impact as divorcing and *not* remarrying (although this clearly depends on certain assumptions)

- Postponed marriage and child birth reduce the average care pool slightly, but this can be offset if the assumed upper age of caring were extended to say age 80 or 85 i.e. assuming frailty is postponed[29]

- The peak age for the number of available carers is typically in the mid to late 40s

Of course the assumptions made in this analysis are simplifications. 'Too young to provide substantial care' and 'of an older age less likely to provide substantial care' are both shorthand and shortcuts for situations in which the advantages and disadvantages to society and to the individuals concerned might tip one way rather than another based on what we know of the patterns of, for example, participation in full-time education or illness-free years or the onset of frailty.

### 3.3 Pivot or sandwich generations

Another way to look at the life-time care cycle is from the point of view of a carer rather than a person needing care. A modern example of why this may be useful is the so-called 'pivot' or 'sandwich' generation. This concept refers to a period in the life of a carer when it is necessary simultaneously to care for children, elderly parents or a partner. [30]

Typically we find that the probability of sandwich years occurring can be boiled down to the birth year of the oldest parent and that of the youngest child. This is because the size of gap is a good predictor of the amount of overlap between a person having to care for an ageing parent and a young person at the same time but clearly other factors are also important.

It can be shown that the greatest risk of occurrence of sandwich years tends to occur in middle age from around age 45 and can theoretically last many years. Much depends on the health and independence of ageing parents and the health of a spouse or partner but also if there are disabled children involved. If any of them have

[28] With the percentage of women for example around 18% of never having a child this represents a potentially sizeable group. Un-partnered men are slightly different as they tend to die at a younger age than women; however, there is much less information on men that have never had children than on women.

[29] This is an important issue since there will be many older carers in future but their health and ability to care will become a limiting factor.

[30] As well as Mooney et al (op cit) an interesting example of where this has been studied is Phillipson, C|: N. Ahmed, and J. Latimer J. (2003). 'Women in transition- A study of the experiences of Bangladeshi women living in Tower Hamlets'. Bristol: Policy Press

a severe disability but are otherwise in good health, sandwich years could last for much longer.

Box 6 conceptualises how sandwich periods may be evaluated using two examples with and without sandwich years. On the horizontal axis is the age of the carer which ranges from birth to 100 years; on the vertical axis is the number of people receiving one kind of care or another. The base case is for a woman who has three children before she is 30. She partners a man who is 9 years older and her mother was 24 years and father 26 years when she was born. In this example there will typically be three separate periods of higher care intensity in a carer's life: These are A. bringing up children; B. looking after parents; and C. looking after a partner.

In case (ii) there are again three children but they are born to the woman between the ages of 29 and 34; her mother was 32 and father 34 years when she was born and her partner nine years older as before, who himself needs care from age 54 due to a long term illness or accident. In this case the expected outcome is for concentrated and partially overlapping phases of care compressed into a smaller number of years as is also described in Box 6.

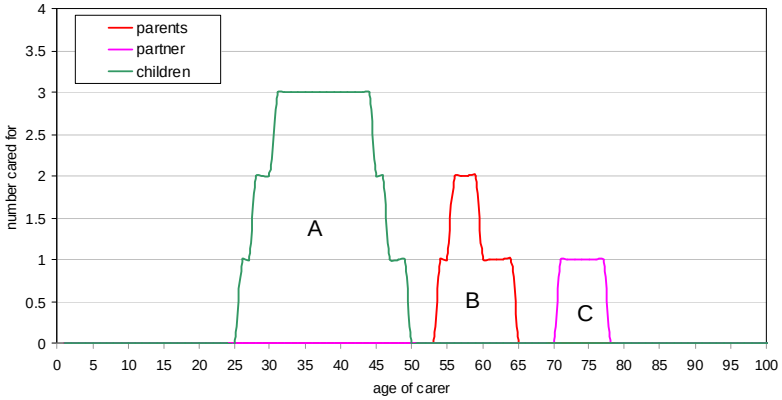
The main cause in this case is the woman having children at a slightly later age and also the age of her own parents. A partner who becomes disabled at a relatively young age only adds to the pressure on the carer. The foot of Box 6 shows a formula for calculating the number of sandwich years based on the youngest child's year of birth and her oldest parent's year of birth, plus the age at which care stops for a child and starts for an adult.

Other examples can be envisaged by varying the number of children, parents etc. by birth years and the start and end ages for which care is required. In the case of children with learning disabilities the period of care is more protracted and could last the life time of the disabled child or the remaining life of the carer; similarly elderly parents with dementia may require long years of care and also a partner with a disabling disease such as multiple sclerosis.

It is impossible to enumerate all possible cases but there are some that give more cause for concern such as young people who care for parents before they have children themselves. Presently, there is little information on families or on birth order to understand how many and what type of families are affected, although it would be possible to construct surveys that could provide such information. Such a model has the potential to be able to project care horizons and inform decisions for example about family and career planning, and care choices in middle and later life.

### 3.4 A snapshot analysis of households in a medium sized English local authority

It is apparent from previous sections that family and household demography are key factors in understanding patterns of care especially when the wider definition of care is included in the analysis. There are huge amounts of anecdotal information about specific families and their care needs which are collected though personal contact or word of mouth which support our general findings.

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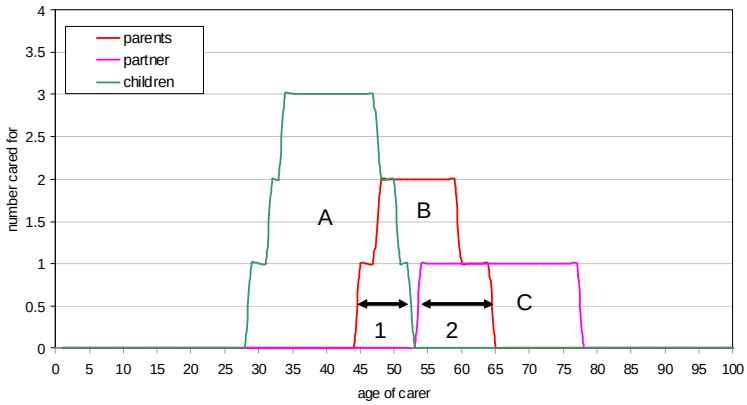



(ii)

**Box 6: Sandwich or pivot years**

**Key: (A) bringing up 3 children until they reach 18; (B) looking after elderly parents age 80+; (C) looking after partner.**

Base case in chart (i): (A) From 26, age at birth of first child, to 49 when last child reaches 18; phase (B) from age 54, when father reaches 80, to 64 until mother dies; (C) from age 71, when partner reaches 80, to 77 when partner dies. Total care years are 39 with no sandwich years.

Sandwich case in chart (ii): (A). From 29, age at birth of first child, until 44, carer only looks after children; phase (A + B) from age 45 to 52 when last child is 18, carer looks after children plus elderly parents; phase (B + C) from age 54 to 64 carer looks after elderly parents and disabled spouse; (C) from age 65 to 77 carer only looks after disabled partner. The first sandwich period is denoted 1 and second sandwich period is denoted 2. Total care years are 35, of which 17 are sandwich years.

**How to calculate the expected number of sandwich or pivot years**

Assume 3 generations with the middle generation caring for the generation either side. If the age at which children attain independence is L and the age at which old age care starts is U, then the condition for sandwich years to occur is $s - f > U - L$, where $s$ is the youngest child's year of birth and f is the oldest grand parent's year of birth, with the number of sandwich years given by $(s - f) - (U - L) = n$

However, we struggle to obtain statistical information about families and households which would be helpful to local providers and agencies in the care sector. For example, our understanding of the amount of unpaid care provided in UK at local level is based on the 2001 Census. Not only is it long out of date but information is unavailable for local area analysis where the need for such information is arguably greatest.

Official statistics on the number and sizes of households in local authority areas are also very limited in terms of household types, population size and geography. They do not distinguish households where there are people receiving care, older households with people living alone or other types of household. Yet better information of this kind would help to in the identification of need and assist with planning and decision making.

In this section, using a specific example, we consider how these gaps could be partially addressed using routinely available administrative information. It is partial because data are only available at the level of the household and not at a family level which will typically be geographically dispersed among several households. However, the data are excellent for identifying household at one type of risk or another, their number and the population living in them.

We base our illustration on a snapshot of local data from one medium sized English local authority of 77.5k households and population of some 200,000 (see Box 7).[31] We divide households into eight types: family households (A); lone parent households (B), adult households with at least one person age 65+ (C); one-person adult households aged 65+ (D); three generational households (E); co-habiting adult households no children (F); single adult households no children; and other households (H).

Box 7 shows that half the population of this town live either in 2-parent family households or cohabiting adult households (rows one and two of the table). Type A family households are over twice as common as type (B) lone parent households although in general the proportion of lone parent families has been increasing. The average size of lone parent households is significantly smaller as might be expected.

Households with at least one older person (i.e. types C, D and E) account for 22% of all households and 18% of the population, together with a marked tendency for the oldest old to live alone – females more so than males. Single or cohabiting households with no children, Types F and G, account for most of the rest. Type H households, a small residual group, includes several unusual structures, such as split generation households with no one of working age, or student households.

It is not possible using these data alone to identify caring households explicitly unless other data are first linked (e.g. data provided social services on current users). However, we can speculate that a household with a carer or a person being cared for will be under more financial strain than a household that does not. A final column added to the table in Box 6 indicates the percentage of households on benefits in order to show this relationship.

[31] The methodology using a range of local administrative data sets and is collectively known as 'neighbourhood knowledge management' or *nkm*. Further details and examples of studies can be found at www.nkm.org.uk

On average we find that 25.7% of households receive benefits in this population. However, the results show that the households most likely to struggle financially are types B, D and E. These are lone parent households, older people living alone and three generational households in which the proportion that are on benefits is approximately 1.5 times the average. This information is also plotted in the accompanying bubble chart in Box 7.

An important case is households with children as their number can affect the levels of child poverty, child care needs, and educational opportunity. The data show that 29k of the 77k households in this population have at least one child and 7.3k households three or more children. The evidence of Table 4 confirms that households with more children face greater financial challenges. For example:

- the percentage of households in receipt of benefits does not show any appreciable difference up to two children but with three or more children it rises steeply

- with six or more children benefit entitlement averages more than 50% but these cases account for only 0.2% of all households

- the accompanying likelihood of living in social housing also increases appreciably when there are three or more children in a household

Further analysis shows that differences in age between children in a household also matters to a degree. Thus, a household with 4 children aged 0-5 is 2.6 times more likely to be on benefits than one without children; but if they are of school age then it is only 1.8 times.

| number of children per household | number of households | % of all household | % of households on benefits | % living in social housing |
|---|---|---|---|---|
| 0 | 48,591 | 62.7 | 23.7 | 12.3 |
| 1 | 11,590 | 15.0 | 25.7 | 12.1 |
| 2 | 9,680 | 12.5 | 25.9 | 12.7 |
| 3 | 4,382 | 5.7 | 34.3 | 16.4 |
| 4 | 2,039 | 2.6 | 41.5 | 18.7 |
| 5 | 737 | 1.0 | 47.4 | 20.4 |
| 6 | 290 | 0.4 | 49.7 | 19.0 |
| 6+ | 168 | 0.2 | 51.2 | 18.5 |
| Total | 77,477 | 100.0 | 25.7 | 12.8 |

*Table 4: An analysis of households with children by benefit status and tenure*

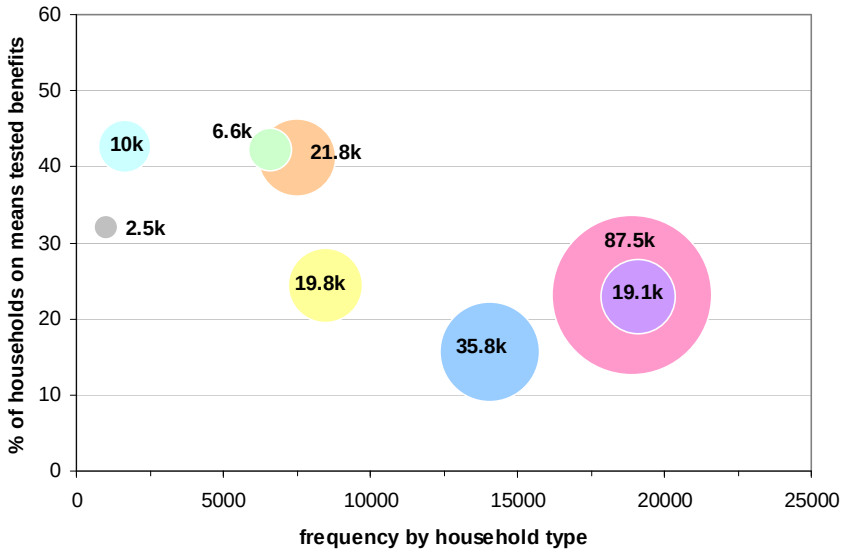



*Chart shows percentage of households on means tested benefits by household type. Bubble size is proportional to population*

**Box 7: Household structure of a medium sized English town**

| House-hold type | household type | Number (000s) | population (000s) | pers. p. house-hold | % house-holds on benefits |
|---|---|---|---|---|---|
| A | Families + dependent children | 18.9 | 87.5 | 4.6 | 23.1 |
| B | Single parent households | 7.5 | 21.4 | 2.8 | 41.2 |
| C | Older cohabiting households | 8.5 | 19.8 | 2.3 | 24.3 |
| D | Older person living alone | 6.6 | 6.6 | 1 | 42.1 |
| E | Three generational households | 1.7 | 10.0 | 6 | 42.6 |
| F | Cohabiting adults no children | 14.1 | 35.8 | 2.5 | 15.5 |
| G | Single adult households | 19.1 | 19.1 | 1 | 22.8 |
| H | Other households | 1.0 | 2.5 | 2.4 | 31.9 |
| | total | 77.5 | 202.7 | 2.6 | 25.7 |

*Table shows households and population by type and percentages on benefit*

- Of 202k people, 87.5k live in family households. The next largest groups are cohabiting adults with no children (35.8k), followed by single parent households (21.8k) and by older couple households (19.8k).

- Older people living alone (population 6.6k), single parent households (21.8k), and 3-generational households (10k) are income poorest. Together they make up nearly 20% of the population with over 40% on means tested benefits (average 25.7%).

- If households are broken down by number of children into smaller age groups, there is a clear relationship between income poverty, the ages and number such that households with young children are worse off than with older children.

- For example, a household with 4 children aged 0-5 is 2.6 times more likely to be on benefits; but if they are of school age then it is only 1.8 times. If there are 2 children aged 0-5 and 2 children aged 6-16 then the odds are 1.6 x 1.3 = 2.1 times, because odds are multiplicative.

In conclusion, the caring commitment in large family households is not only likely to be greater but it also depends on the number and ages of children living in the household. Enumerating different types of household in an area therefore helps with planning, prioritising and resource allocation.

The above is intended as an illustration of how certain information gaps can be filled, but the challenge for local authorities is to be able to link these data with other data such as those available from children's and adult social services. In section 4 further suggestions and ideas are given on how to link data and capitalise on underused information assets. [32]

### 3.5 Working and caring

Previously we showed that the life cycle for caring has distinct patterns whether looked at from the point of view of the person being cared for or the carer. On the question of combining work with care, employment data are very clear that the ages when male and female economic activity rates differ most is between age 25 and 40, the peak years for rearing young children.

This gap declines from age 40 as women return to work and reaches a minimum at age 50 before increasing steadily again to age 60 when women start to draw their state pension. Set against this pattern we note that the main trend in the last 25 years or so in labour markets has been the increased participation of women and of part-time working.[33]

At the same time the rate of economic activity among males fell from its peak in 1990, levelling out at 71% since. The comparable figure for females is a rise from 47% in 1984 to 52% in 1990 and then gradually increasing thereafter to around 57% today. If we combine males and females then participation rates have remained broadly static at between 62% and 64%.

The change in female participation rates is of importance because women are the main carers in society. The changes to female participation rates that have occurred spring mainly from the growth in flexible part-time working, a rise in the availability of jobs that suit women's needs and skills, the greater availability of child care and more favourable labour market policies making this possible.

With increases in state pension age for women between 2010 and 2020 and further increases anticipated, women will be under pressure to work for longer but the evidence is that female rates fall off when they are in their 50s. Using data from ELSA[34] we analysed economic activity rates among older households with at least one person aged 50+ in order identify any common factors.

Box 8 provides summary details our findings. The results show that in the age range 50-59 individuals are much more likely to be economically active if they are in good health, educated, a home owner, and cohabiting, and male. The odds of working increase 1.5 times if a person does not have any caring responsibilities, but the effect is not as great as it would be for someone in good health or a home owner.

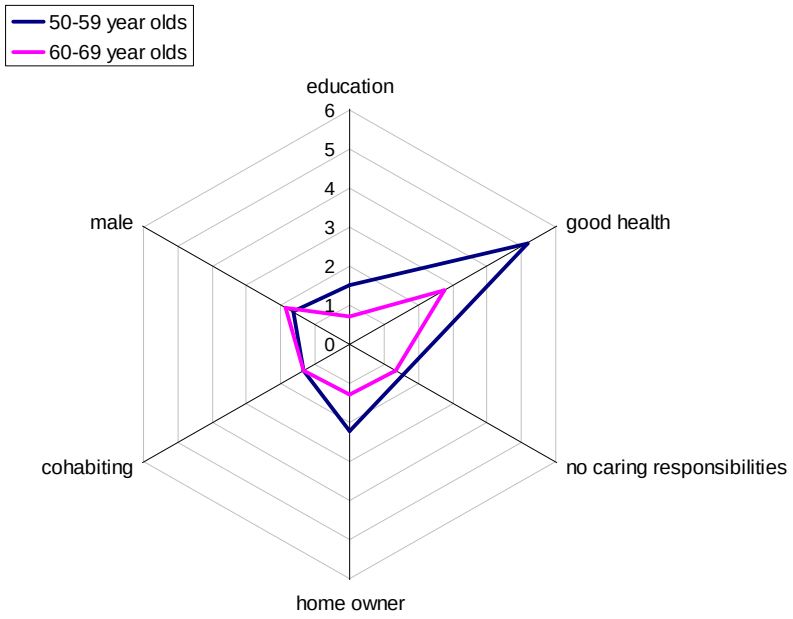
[32] For further examples of case studies using joined up administrative data see 'neighbourhood knowledge management', at www.nkm.org.uk
[33] Source Labour Force Survey
[34] English Longitudinal Study of Ageing

For those aged 60-69 the odds of being economically active are reduced, as might be expected since many will also be retired pensioners. People with some education tend to retire sooner, but good health and being male are still the important predictors of economic activity in this age range. However, having no caring responsibilities and cohabitation status also remain important.

What insights do we take from this example? The UK population is ageing but economic activity rates are static and for people in their 50s there is an accelerated withdrawal from work long before state pension age. In the case of women this starts from age 50 with a 5 year lag for men before they attain similar rates. At the same time, people will be expected to work for longer because of increases to state pension age.

The evidence suggests that those least able to work are more likely to be drawn from people who are less educated or well off, not in good health, and have caring responsibilities, or all of these. Unless there are significant changes in this pattern, rising pension age is therefore likely to impact on other parts of the welfare system among these groups, and the anticipated savings from higher pension age will be reduced as a result.

The findings also show that health is easily the most important factor in continuing to work and so improving health among people in these age groups will provide a double economic benefit in terms of more people able to work and fewer carers. The implications of the above are that strategies that reduce the demand for care, for example as a result of health improvements should be part of the strategic mix.




**Box 8: Influences on labour market participation among people aged 50- 59 and 60-69**

A model was developed to estimate the contributions of different household and personal factors on labour market participation among people age 50+. The chart above shows the relative strength of each factor based on statistical odds.

Odds with a value of 1 indicate that a given factor has no measurable influence whereas anything above one means that the given factor is correlated with being economically active; if it is less than one the effect is the opposite.

The results show that among the 50-59 age group being in good health is the most important predictive influence on economic activity status with odds of 5.2. The next most important is being a home owner with odds of 2.2 followed by being male with odds of 1.6.

The results show that individuals with no caring responsibilities are 1.3 times more likely to work, have roughly the same effect as co-habitation status. The factors are multiplicative which means that if a person is in good health and a home owner for example the combined odds are 5.2 x 2.22 = 11.44

| factor or influence | age 50-59 | age 60-69 |
|---|---|---|
| education | 1.5 | 0.7 |
| good health | 5.2 | 2.7 |
| no caring responsibilities | 1.5 | 1.3 |
| home owner | 2.2 | 1.3 |
| cohabiting | 1.3 | 1.3 |
| male | 1.6 | 1.9 |

# 4. Strategies for meeting future demand for care

## 4.1 Options

We have painted a picture of receding state provision for care and care related services, of rising pension age, reforms to social security benefits and health care, and a rapidly ageing population. In addition, the economy has been severely impacted by the global recession and the future general economic climate remains unclear. The Coalition Government's approach is to re-position the UK economy to enable it to mount a long term economic recovery.

The main anticipated effects of economic restructuring are changes in the pattern of employment with much fewer and less well remunerated public sector jobs and hoped-for growth led by the private sector. Moreover, this growth is likely to be much slower than the UK has been used to over the past two decades mainly because of factors relating to the global economy and transitional restructuring but also because of demographic ageing.

For the unpaid carer, it might be imagined that these changes would not affect them because they are not impacted by changes in employment. However, they would be mistaken because public services are becoming scarcer and less accessible. Other things being equal, their combined effect is likely to increase pressures on carers to work, whilst at the same time increasing the amount of care they do.

The picture will be slightly different for older carers insofar that they are retired; however, because of demographic and other factors it reasonable to expect these additional pressures to cause a widening and deepening of the age range in which unpaid care is mainly provided. The issue is thus how to manage this transition such that any reformed system of care is sustainable at the point when the number of older people starts to plateau, as it will eventually.

There are four strands that can be considered. These are:

- Prevention strategies that are directed at improving or maintaining health and so limiting the growth in long term conditions that require long periods of care especially in older age

- Improving productivity of caring by organising care so that, in simple terms, the ratio of carers to those cared for is more sustainable as the population ages and demand for care increases

- Organisational change to remove administrative barriers and create fewer boundaries that currently make it difficult to obtain information and restrict co-operation between care providers

- Greater support for carers to increase their skill levels, enable them to balance work and care; access to financial advice on paying for care, financial products and benefits entitlement; and help with finding employment

*4.1.1 Prevention strategies*

The concept of prevention may be thought about on different levels. At the population level, we are familiar with the health benefits of clean water, improved sanitation, good housing, nutritious diets etc. (usually termed 'primary' prevention). We are also familiar with the role of vaccinations in preventing diseases like influenza each winter ('secondary' prevention) and help for older people with their energy bills. We also know that inequalities in wealth and income are correlated with unhealthy lifestyles and lower life expectancy especially among poorer socio-economic groups.

As life expectancy has increased and previous health threats have been successfully addressed, so the focus of prevention is to tackle the next major threat to health. The modern focus of attention in primary prevention terms, and where the prevention frontier is currently drawn, is the threat to health resulting from long term chronic conditions caused by adverse unhealthy life styles. Habits such as smoking lead in due course to life threatening conditions and so to a co-morbid state of health of involving several long term disabling conditions and hence potentially greater dependency.

By delaying the onset of chronic conditions it is possible to reduce life cycle health care costs and potentially social care costs too. Those with lower lifestyle related health risks such as non-smokers, regular exercisers and with a normal Body Mass Index evidence a delayed onset of impairment of approximately 5 years and a significantly reduced disability at the time of death.[35] Fries (1980) called this process the 'compression of morbidity' and claimed that 'whether the period of morbidity is shortened depends very much on the average age of onset of the first marker (e.g. diagnosis of hypertension or first heart attack).'

Chronic diseases endure for life and the earlier the onset of the first chronic disease, the greater the likelihood is of a second or third disease occurring. Each new diagnosis or step up in severity increases health and care costs through more doctor visits, prescriptions, social care etc. However, also having significant preventive benefits is the timeliness and appropriateness of health, care and other interventions for people that already have disabling conditions whether it is care in kind or financial help. Giving help to people to regain skills after a fall in order to prevent them having another fall or providing financial help to pay for high energy costs in winter months are two well-known examples.

Many social care interventions may be of a practical nature of the 'light bulb replacement or pipe repair' variety or entail the maintaining of social networks. Judgements about their value are much harder to make because the level of proof needed to make organisations change their practices can be high and the time needed to do so rigorously is very long (although this does not seem prevent organisations from cutting services when resources are tight). This argues for a holistic approach to care based on a package of interventions linked together within a care plan.

[35] Vita, A.J., R.B. Terry, H.B. Hubert, J.F. Fries (1998). 'Aging, Health Risks, and Cumulative Disability'. New England Journal of Medicine 338:1035-1041.

| | *Intervention type* | *Rationale* | *Comment observation* | *Carers have access to better more personal-ised services* | *Carers able to lead more indepen-dent life* | *Carers have access to financial support and advice* | *Carers enabled to remain mentally fit and healthy* | *Carers better informed* |
|---|---|---|---|---|---|---|---|---|
| **A** | **<u>Prevention</u>**<br><br>Improvements in the health status of people through prevention of long term conditions | Would moderate growth in health care costs over time and enable people to work for longer and live independently | Long term strategy designed to delay demand for care and enable shorter care durations. Needs better understanding of how to change adverse health behaviours | | ■ | | ■ | |
| **B** | Better care co-ordination leading to timelier interventions and greater efficiency, and joined up services | Better care co-ordination and holistic assessment enabling better care outcomes such as delayed transfer to nursing care reduced end of life acute care costs, and faster access to support services and advice | Large scope for improved co-ordination and outcomes and timelier intervention. Needs to be supported with better management information, advice and case management. Users of care and their carers need to be in control. | ■ | ■ | | ■ | ■ |
| **C** | Reduced demand for acute hospital beds through better case finding | If high risk cases of hospital admission can be identified early there is evidence that bed-days and A&E attendance are reduced | Effective case finding and more responsive assessments would reduce need for crisis interventions.<br>Costs born by social care, but savings accrue to acute care. Primary care an important mediator in this process. | ■ | ■ | | ■ | |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **D** | Re-ablement | To help person recover after a crisis such as a fall and hospital stay, through home adaptations and care packages. | Without help to rebuild independence carers would struggle. Costs born by social care and community health , savings made in acute care | ■ | ■ | | ■ | |

*Table 5: Examples of interventions that can reduce care costs and the outcomes on carers*

Table 5 lists four preventive interventions, A to D, and their rationale. The selected impacts on outcomes for carers shown in the columns to the right are based on the Government's vision for carers and are common to all other tables in this section:

- those that give better access to care and allow carers to lead a more independent life;
- those that provide access to advice and information (including financial advice);
- those that enable carers to stay healthier for longer and keep them better informed.

Not every intervention impacts on every outcome and so only the main expected impacts are shown.

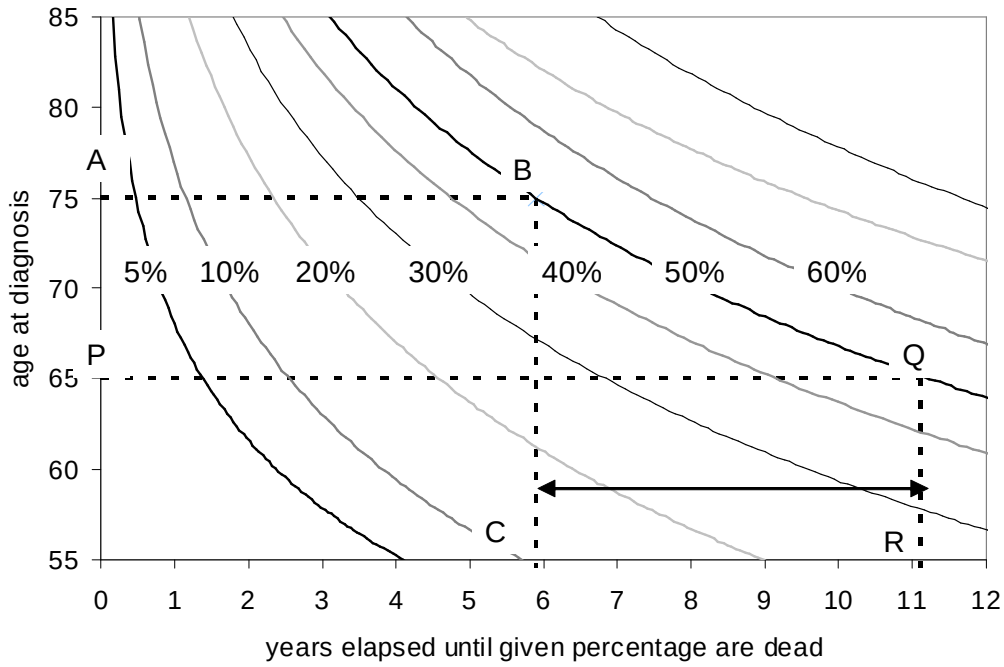
(a) Example 1

Most people experience one or more long term conditions in life but delaying the onset of chronic diseases can increase healthy life expectancy (i.e. increasing the number of disease free years), so potentially reduce health and care costs over the life cycle. For example, a person that is diagnosed with a condition such as hypertension or who has a stroke in say their 70s or 80s is less likely to survive for as long as a person who is diagnosed with the same conditions in their 50s. Younger people are more likely to respond to treatment and live for longer albeit in a diseased state, whereas for older people treatments are less effective or life-prolonging.

An example is shown in Box 9, based on work by Alder et al[36] which involved an analysis of a data base with over 3 million medical records in total including people diagnosed with COPD (chronic obstructive pulmonary disease), a disease usually associated with long term tobacco smokers. The chart shows that a person diagnosed with COPD at 65 (point P) has a 50% chance of dying within 11.1 years (point A); however, if diagnosed at age 75 it is only 5.9 years. This individual would potentially live 10 more years than the first person without this condition and 5.9 years with it. So that, crudely, this represents 11.1-5.9 = 5.2 fewer years of health care for this condition.

At the population level we would therefore expect delays in the onset of conditions such as diabetes and hypertension that are precursors to more serious long term conditions to have a beneficial effect by reducing the prevalence of disease, reducing health and care costs over the life cycle. **In other words, policies and actions that delay the onset of disease are likely to be less costly than actions that deal with the consequences.** This is hence an example of the 'the compression of morbidity' hypothesis mentioned above.

[36] Alder, J., L. Mayhew, S. Moody, R. Morris and R. Shah (2005). 'The Chronic Disease burden: An analysis of health risks and health care usage'. London: Cass Business School.




**Box 9: How prevention of chronic disease could save on health and social care costs**

The above chart is based on people diagnosed with COPD (Chronic Obstructive Pulmonary Disease), a condition frequently brought on by smoking tobacco. The vertical axis shows the year of diagnosis and the horizontal axis the years elapsed until the given percentage of diagnosed people are dead.

Point A: People diagnosed with COPD at age 75; their median life expectancy is just under 6 years, point C.

Point B: People diagnosed with COPD at age 65; their median life expectancy is just over 11 years, point R.

The difference R minus C, 5.2 years, represents the additional number of years that a 65 year old would be expected to need health care as compared with a 75 year old diagnosed with the same condition.

In general, measures that delay the onset of chronic disease will reduce the prevalence and the costs associated with treatment of that disease. In addition, it may be speculated that the prevention of that disease may avert or delay the diagnosis of other commonly associated conditions (e.g. hypertension, coronary heart disease).

The example of smoking can be highlighted as one which lowers the age of diagnosis of long term conditions. Of all risk factors, smoking remains the most important underlying causal factor in lung cancer, but also long term conditions such as heart disease and COPD and is hence a major cause of avoidable deaths. Smoking is estimated to account for about 110k deaths a year in the UK or around 18% of the total.

It may be argued that since smoking results in earlier death, life cycle health and care costs would be less, although this would be false. Unpublished research by Karlsson et al[37] found that non-smokers enjoyed 6 to 7 more years of healthy life expectancy than smokers; in addition smokers in their 50s were less likely to be in work and more likely to be on income and disability related benefits.

If all smoking were to cease it is calculated that health life expectancy would increase by about 1.5 years based on current smoking prevalence in adults. To achieve the same effect by spending more on health care would require a 50% increase in spend (or about £50bn) based on global evidence of the relationship between health care spending and healthy life expectancy.

Over time it can be speculated that the benefits of healthier lifestyles would be substantial, the more so if periods of illness and disability are confined within short periods of time at the end of life. If 10% of the population were disabled and needed care, then 8 years of an average life span of 80 years would be dependent on health and care. If this could be reduced by say 20% then this period would be reduced to 6.4 years with corresponding savings in the demand for carers with obvious benefits to society.

*(b)* Example 2

There are many organisational models and types of care services that can be provided but convincing evidence on which are best is thin. The lesson from the Department of Health's POPP programme[38] is that interventions vary hugely, for example whether it involves signposting or information providing, case finding and assessment, care co-ordination, actual service delivery or all of the above.

However, the details are important since how the services are organised and delivered as well as what they provide appears to make a difference. It is important to emphasise that the individual with the clearest picture of who they get support from is usually the person who needs support. The problem that arises is when they do not know that they need support, or if they do, do not know where to get it.

In a prevention sense timing is of the essence and so a more productive way to evaluate differences is to look at outcomes from a timeliness perspective as well as by intervention type. For patients, these outcomes may be life saving, life extending or life improving (i.e. in terms of greater well being, lower dependency); for the health and care system outcomes may include fewer days in hospital, lower care intensity, fewer emergency call-outs and so on. The knock-on effect could include reductions in hospital beds, shorter waiting lists for elective care, delayed transfer to residential

[37] Cass Business School press release: 'Giving up smoking adds seven years to good health'. June 2007

[38] Department of Health (online) Partnerships for Older People Projects http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/PartnershipsforOlderPeopleProjects/index.htm

care and higher quality services overall. It can be argued that as long as patient outcomes are the same or improved, interventions that cost less are generally to be preferred.

A key difficulty arises however in proving whether a good outcome is the result of a specific intervention, or whether the improvement would have happened anyway e.g. because another service would have stepped in. This is called the 'attribution effect'. However, taking a broader view it is arguable that the whole care pathway is more important than each individual intervention. This generally called the 'whole systems approach' to care and support.

In a major experiment to test out different types of interventions the POPP programme was set up to provide improved health and well-being for older people via a series of individual projects providing local services to over 250k older people in which carers and the caring profession played a central role. The projects ranged from low level services, such as lunch clubs, to more formal preventive initiatives, such as hospital discharge and rapid response services.

Twenty nine local authorities were involved as pilot sites, working with health and voluntary sector partners to develop services, with funding of £60m. Overall, the evaluation found that the reduction in hospital emergency bed days resulted in considerable savings, to the extent that for every extra £1 spent on the POPP services, there was approximately a £1.20 additional benefit in savings on emergency bed days. Reductions were also seen in physiotherapy/occupational therapy and clinic or outpatient appointments with a total cost reduction of £2,166 per person.

Most POPP projects had an impact on carers as well as on those needing care although this was rarely quantified explicitly. Examples of projects focussing on carers included a rapid intervention scheme to support carers in urgent situations in Wigan; in Somerset a service to provide advice information and referral services; in East Sussex a 'sign-posting' service that included some financial support for well being and handyman services; and in Leeds a 'dementia' café provide advice and information to carers and home support service.

In the London Borough of Brent, the POPP pilot was based around the Integrated Care Co-ordination Service (ICCS). Clients referred to ICCS were just below the critical threshold to qualify for social care.[39] Clients whose average age was 80 were assessed and, depending on need, provided with basic services. This included traditional care and support but also help with as such odd jobs around the home, assistance with welfare benefits etc., and putting people in touch with community health services as appropriate.

Referrals to the service came from a wide range of sources including GPs, the voluntary sector and social services itself (who referred people just below 'critical' on the FACs scale). Suppliers of services included the statutory (e.g. health services, local authority services, pension service), voluntary (e.g. befriending, re-housing, odd jobs) and private sectors (e.g. opticians). The evaluation showed that through earlier intervention than would have been the case if social services had assessed the case,

[39] Based on the FACS rating system: Fair Access to Care Services framework, which has four bands: critical, substantial, moderate and low.

between 14 and 28 bed-days a year, 2.9 to 5.9 admissions per person, and between 2.8 and 7.8 A&E attendances were avoided.[40]

Other findings included a reduction in the number of people going into funded residential care by deferring or delaying transfer; people connected to services that substituted wholly or in part for funded packages of care; and reductions in the number of falls post intervention. By comparing the profile of ICCS referrals to those made to Older People's Services it was also evident that ICCS was more likely to be in contact with harder to reach and income deprived groups especially those living alone or on means-tested benefits.

Why was there this difference? Because of severe resource constraints, Older People's Services mainly dealt with urgent cases that were assessed as critical or substantial bracket under FACS, for example providing services to people discharged from hospital following a serious event or episode. As most people referred to ICCS or Older People's Services were reasonably matched in terms of underlying health conditions and age, it was an opportunity to compare their outcomes according to which care pathway they followed.

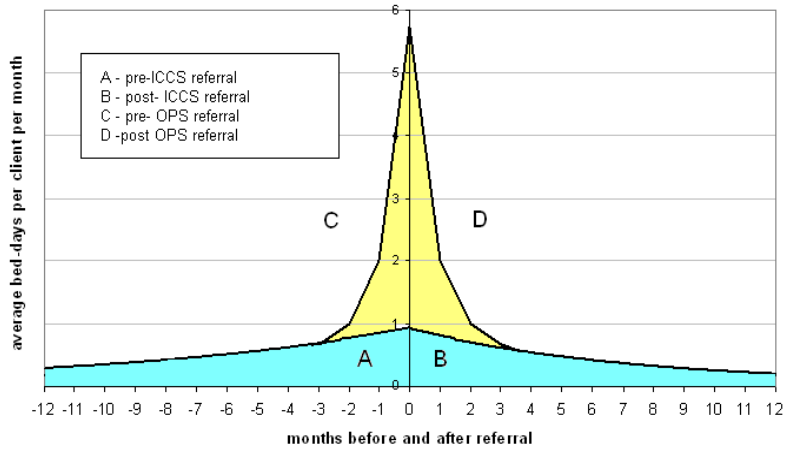
A number of different strands could be identified. For example, it was found that the mortality rate of people referred to ICCS did not differ significantly from those referred to social care in the 12 months following intervention. In addition, dependency was not reversed, in other words similar proportions of clients still needed help with feeding, washing, etc. Whereas these outcomes were pathway independent, there was a reduction in the frequency of falls and a moderate increase in well-being among ICCS clients.

However, it was also found that proximity to death was strongly correlated with care pathway. A comparison of those referred to ICCS and those to Older People's Services showed that ICCS clients consumed fewer bed-days in the year before death than pathways which only involved adult social care. Specifically, it was found that ICCS clients spent an average of 16 bed-days in hospital as compared with 38 days by those using mainstream social services, resulting in a saving of 22 days on average.

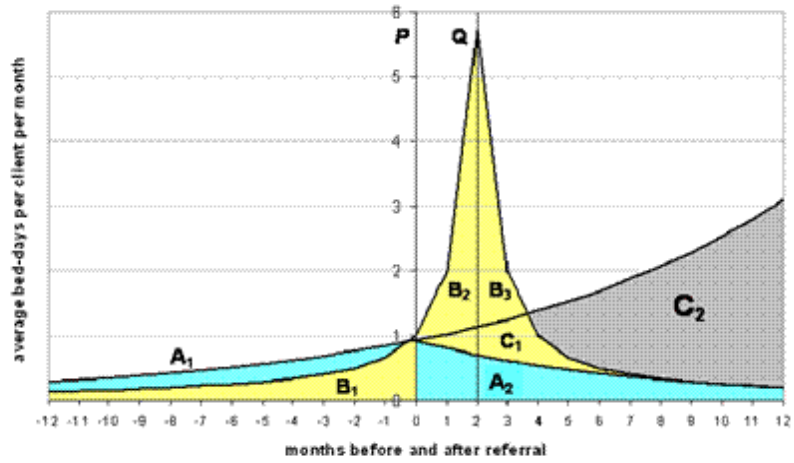
What do we learn from these POPP examples? Firstly, that investment in care services can reduce overall health care costs and those pro-active and faster responding services do better than services that respond once the crisis or accident has occurred. In terms of the economic case, the timing of interventions plus case selection are arguably the two most important aspects for services which proclaim to have preventive benefits.

Box 10 analyses how the timing of an intervention affects hospital bed-days using actual data collected during the Brent POPP pilot. Chart (i) shows how bed-days pivot at the point of intervention based on two care pathways, either referral to the ICCS or referral to social services. Chart (ii) shows the mechanisms by which bed-days are potentially saved and below calculates the consequential hospital bed-days avoided according to each.

[40] Mayhew, L. (2009). 'On the effectiveness of care co-ordination services aimed at preventing hospital admissions and emergency attendances'. Health Care Management Science. Vol 12(3), 269-284




(i)




(ii)

**Box 10: Admission rates of older people receiving either Older Peoples Services (OPS) or ICCS and early prevention service in the months before and after intervention (Key: Yellow, OPS; Blue, ICCS, Grey, projected)**

The charts above compare hospital bed day usage in months before and after intervention according to one of two care pathways: ICCS or Older Peoples Services

- $A_1$: ICCS pathway in which clients consumed an average of 6.5 bed-days each in the 12 months prior to intervention
- $B_1$: Clients using OPS pathway in the 12 months up to the point where they would have received ICCS intervention consumed on average of 3.6 bed-days each
- $A_2$: Bed-days used by ICCS clients 12 months post-intervention equate on average to 5.5 bed-days per client
- $B_2+B_3+C_1$: This is the bed-day excess incurred by OPS clients compared with clients referred through ICCS and accounts for 13.4 bed-days per client
- $C_1+C_2$: Avoided bed-days 12 months post ICCS estimated to equate to 16.2 bed days per client assuming no crisis intervention is triggered

ICCS was designed to intervene at an earlier point in the care cycle through improved case finding, and earlier assessment of all relevant risk factors (e.g. state of health, living alone, unsuitable accommodation, very low income, no obvious carer). Although it is not possible to predict exactly the timing of an intervention relative to when a crisis would have occurred, an analysis of hospital admission rates suggested around two months.

Case selection was important since there would not be cost savings if the wrong types of individuals were supported (e.g. those with acute health problems who would make a full recovery or people at the end of life). In this regard, ICCS clients typically had 2+ long term conditions such as heart disease, mobility problems, respiratory diseases, mental illness, diseases of the nervous system or any combinations thereof. There were no referrals of people for example with cancer.

Following assessment clients were put in contact providers from the voluntary, private as well as statutory sectors. The average contact and follow-up time for each intervention was 3 months. Savings were made on health care costs but there were also savings to social care through a reduction in more expensive care packages leading to lower pathway costs over a typical care cycle. The view of the evaluation team was that if implemented nationally ICCS could lead to national savings of £2bn a year on health care costs alone.

However, the realisation of this figure comes with an important caveat, namely that for a sustainable system savings would need to be recycled, for example through reductions in the number of hospital beds. In summary, ICCS, and services like it, can be thought of as examples of a form of social investment that could be attractive to private sector investors as well as to the public sector. For them to succeed, good management information is also essential in order to justify their existence, a theme to which we return below.

*4.1.2 Productivity improvements*

Caring is a labour intensive activity and so any increase in the number of people needing care will absorb disproportionately large numbers of people as compared with other activities such as teaching school children. It follows that an ageing population is likely to stretch the supply of carers and increase carer costs in future years although as we previously noted many of the carers will be themselves older.

Nevertheless, without significant productivity gains within the care system, the unit costs of paid care are likely to grow. More carers would be obliged to give up work in order to care, with adverse effects on the general economy if the number needing care expanded faster than the rate of growth of the population. In simple terms, productivity can be defined as the amount of care supplied in suitable units divided by the number of carers, or measured in monetary units by the total cost of care.

There are technical issues about whether and how to include unpaid carers in any calculation but even without such information it seems obvious that there are a number of ways that productivity could be improved. It could be improved by reducing what is required without changing resources or by making resources go further but a third and most expensive option is to increase the resources needed to produce what is required.

On the supply side, there are a number of ways of tackling low productivity – for example by increasing the skills and knowledge of the people who provide care. How

care is organised is important especially where it results a better use of time – e.g. care workers spending less time travelling between clients. Creating enabling environments that support independence (e.g. in housing, transport, and shopping) can also increase productivity, but quality is important otherwise modes of care would drift towards the cheapest and lowest common denominator.

It is generally argued that care delivered in the home is cheaper than care in other settings such as residential care and better for individuals needing care; however, this judgment depends on many factors and the decision should be framed in terms what is best for the individual. It is important to think about the opportunity costs of alternative uses of resources such as hospital beds and whether they should be closed or kept open.

Table 6 provides examples of where there may be scope to increase productivity (A to D) and the rationale for each. The first example, A, is about case management, in which a professional care worker is responsible for overseeing the care of a person who has been enrolled into a care programme. Better case management leads to improved care co-ordination like the example based on ICCS, one of the POPP projects discussed earlier.

The second example, B, is designed to highlight a gap in data which undermines our ability to calibrate care needs in an area. As already indicated in a previous section, the main source of local information on unpaid care is the Census, whose drawbacks have been mentioned. We show how this can be overcome by making better use of existing administrative data and local surveys to obtain up to date and accurate information about carers and their needs.

Example C concerns Assisted Living Technologies (ALTs) that keep people at home but enable care to continue at lower intensity. ALTs, of which there are two basic types –telecare and telehealth - offer much potential to improve productivity. Recent research published by the Department of Health for example found that, if used correctly, telehealth[41] can deliver large reductions in A&E visits, emergency and elective admissions. More strikingly results also demonstrate a 45% reduction in mortality rates. If these findings could be repeated and if research finds that telecare delivers similar efficiencies, this would be regarded as a breakthrough.

Lewin[42], in a study looking forward to 2030, identifies the main future uses of ALTs. These are delivering better and more cost effective social and health care into homes; providing services which entertain, and stimulate social interaction; encouraging users to get fitter and to adopt healthier lifestyles (wellness services); and enabling older and disabled people to work from home.

Figure 4 below taken from the study brings together several themes of our analysis, especially improved responsiveness, remote caring and higher productivity. It illustrates how services supported by ALTs might help the example of a fictitious couple, Clare and Colin, in their late 70s, to live independent and richer lives at home 10 years from now. These services have both health and safeguarding dimensions on the one hand but also integrate with entertainment, shopping and other functions.

[41] Electronic equipment that monitors vital health signs remotely and personal and environmental sensors that enable people to remain safe and independent in their own home. (Source: ' Whole System Demonstrator Programme Headline Findings' – Department of Health, December 2011).

[42] 'Assisted living technologies for older and disabled people in 2030' - A final report to Ofcom. Lewin et al. Plum Consulting, March (2010).

Example D is about care settings that enable care oversight in larger settings with fewer carers. The example is given of a day centre, but many other types of setting can be envisaged ranging from sheltered housing to retirement villages. These kinds of developments move us away from the traditional view that people should be allowed to remain at home for as long as possible. However, there is clearly a role for developments that enable people to move flexibly into types of accommodation that are suited to their needs in a more seamless progression as dependency increases.

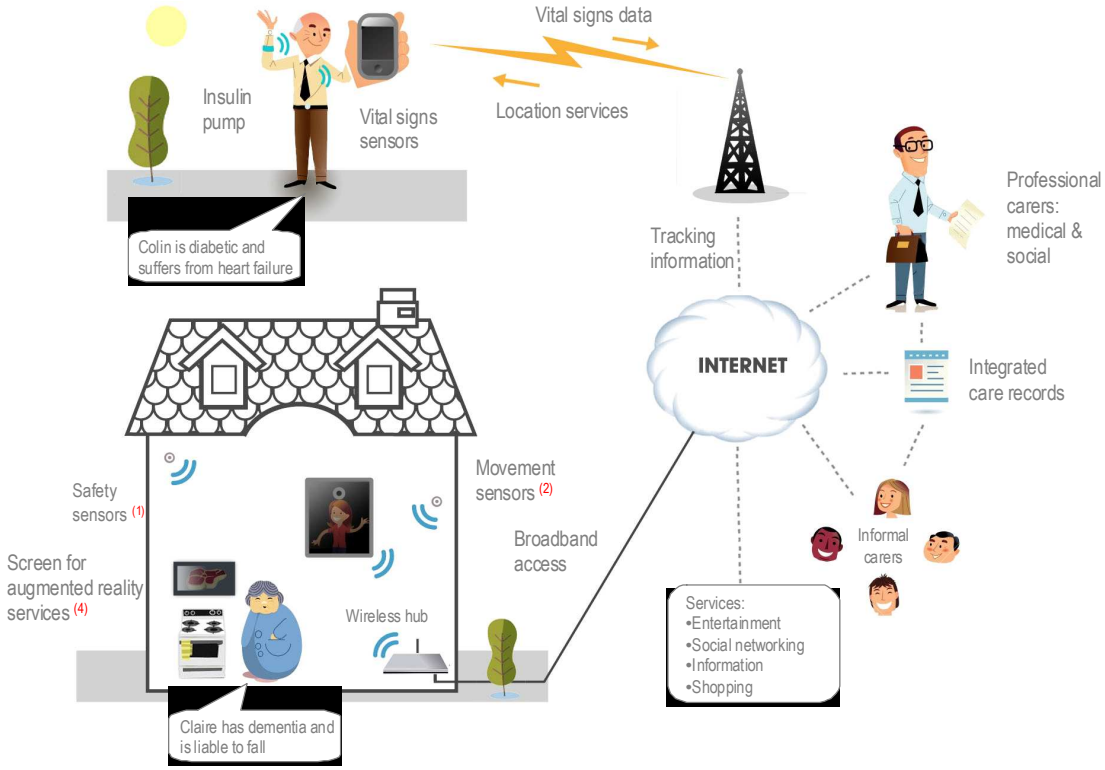



*Figure 4: How ALTs could help Colin and Clare live at home (source: Lewin et al, 2010)*

| | *Intervention type* | *Rationale* | *Comment observation* | *Carers have access to better more personal-ised services* | *Carers able to lead more indepen-dent life* | *Carers have access to financial support and advice* | *Carers enabled to remain mentally fit and healthy* | *Carers better informed* |
|---|---|---|---|---|---|---|---|---|
| **A** | **<u>Productivity</u>**<br><br>Case management | A case manager that has information about all the services supplied to an individual is in a better position to optimise and schedule care | Occurs to some extent but management information about individuals to enable this to happen is not joined together | ■ | ■ | | | ■ |
| **B** | Information about carers | Statistical information about carers is limited to a few sources e.g. the 10-year Census, General Household Survey. Timely local information absent or partial | Improved local quantitative and qualitative information would enable identification of high risk groups, early intervention and better allocation of resources | ■ | ■ | ■ | ■ | ■ |
| **C** | Assisted Living Technologies | Capacity to improve quality of life, carer productivity, access to information, and safeguarding | Needs to be designed and personalised around individual. to obtain return on investment | ■ | ■ | | | ■ |
| **D** | Carer sharing | Any activity that involves fewer carers per person cared for is a potential productivity gain provided outcomes are the same or better | Any form of organisation that has the capacity to reduce the unit costs of care can be considered. e.g. retirement villages, time banks | | ■ | | ■ | |

*Table 6: Examples of interventions that can improve the productivity of care*

| | *Intervention type* | *Rationale* | *Comment observation* | *Carers have access to better more personal-ised services* | *Carers able to lead more indepen-dent life* | *Carers have access to financial support and advice* | *Carers enabled to remain mentally fit and healthy* | *Carers better informed* |
|---|---|---|---|---|---|---|---|---|
| **A** | **<u>Organisational barriers</u>**<br><br>Financial mechanisms to move money between health and social care | Health care savings generated by social care cannot be recycled to improve social care services. | Financial incentives would lead to better social care, increased capacity and incentivise local services to perform better | ■ | | | | |
| **B** | Better management information | Currently information split between social services, GP, hospital and care home. More integrated information accessible to care providers would improve scope for joint working and build care capacity | Effective management of care is handicapped by byzantine systems organised in information silos. | ■ | ■ | | ■ | |
| **C** | Introduction of generic care workers | Care providers able to perform more tasks in person's homes in one visit and so improve efficiency by increasing contact time and reducing handover costs | Fewer agencies and individuals for carers to deal with and so fewer information transactions | ■ | | | | |

*Table 7: Examples of organisational barriers*

*4.1.3 Organisational barriers*

Care frontiers are bounded by the authority or willingness of care providers to make interventions, or commit resources. This in turn depends on factors such as the availability of unpaid care, but also the flow of information between care providers, the person cared for and the target clientele of care agencies. The success or otherwise of communications between providers frequently boils down to organisational issues and so we consider in this section how these can get in the way of delivering better care.

Organisational boundaries exist for many reasons. They include the need to exercise financial control or good governance, protect employees and the need minimise risk and harm to individuals. Boundaries of authority may be enshrined in legislation such as the split that currently exists between health and social care in the UK, to the demarcation of boundaries between professional groups such doctors, nurses, occupational therapists and a range of other professional care workers.

Boundaries are drawn piecemeal over long periods and are the result of previous legislation and reforms, various agreements between employers and professional bodies and so on. Taken individually most changes have a rationale but over time this becomes questionable, if they are the result of incremental change rather than major reform. New polices and practices get locked in to old policies and practices and so on.

By affecting behaviour, boundaries may have unintended consequences. For example, an in-work benefit paid to carers that is withdrawn or is too low may cause greater unemployment among carers. A second example is adult social care services that are shown to reduce hospital admissions may be withdrawn or not provided at all, if the savings accrue to the health services instead of, in this case, local authority providers.[43]

Table 7 provides three examples of organisational barriers. Example A considers the lack of financial mechanism that would enable money to move more freely between health and social care. The example of Brent was given above in which earlier intervention led to fewer hospital bed days but the value of the saving accrued mainly to health. A system that rewarded social care would lead to a virtuous cycle in which successful prevention strategies would be rewarded and sustained.

Example B highlights the problem of 'information silos', which refers to the phenomenon that information is held in several places and that there is no integrated care record. The consequence is that it leads to duplication and conflicting information but also information gaps (e.g. between health providers and social care). Organisational structures limit information sharing and so make it difficult more difficult to manage.

In general, it is much more efficient to develop information systems around the people being cared for in ways that are resilient to changes in organisational boundaries. In this concept, access to information fields by different organisations and the authority to update information is controlled and managed through a matrix of 'permissions' and 'authorities' to address issues of privacy and data protection.

Box 11 is an illustration of the 'silo' problem in which information transactions occur at various points in the system but there is no common access points at which

[43] This was a key finding for example in the POPP programme

access all information. In the diagram there are a minimum of five different providers spanning the statutory, private and voluntary sectors in which the statutory sector itself is split three ways into primary care, secondary care and social care.

Arguably, the more providers there are the greater the scope for human error. With one provider there are no transactional boundaries, two providers one boundary, three providers three boundaries, four providers six boundaries, five providers ten boundaries and so on. If providers occasionally need to meet to discuss a case or a care plan the number of possible meeting combinations of two or more providers escalates even more rapidly: 1, 4, 11, 26, 56…

What would better information enable? Care providers would find it easier to work together and with unpaid carers; health providers could make informed decisions about whether or not to admit or discharge a person from hospital; care plans would have an evidential basis; assessments would be holistic and care managers would be able to manage independently.

Example C refers to professional rather than organisational or information boundaries. Over a long period, care services have become more specialized and professionally demarcated. In a study looking at intermediate care and the prevention of admission and early hospital discharge Mayhew and Lawrence[44] identified up to 22 different services that might be involved in the care of an older person at home supplied by different people.

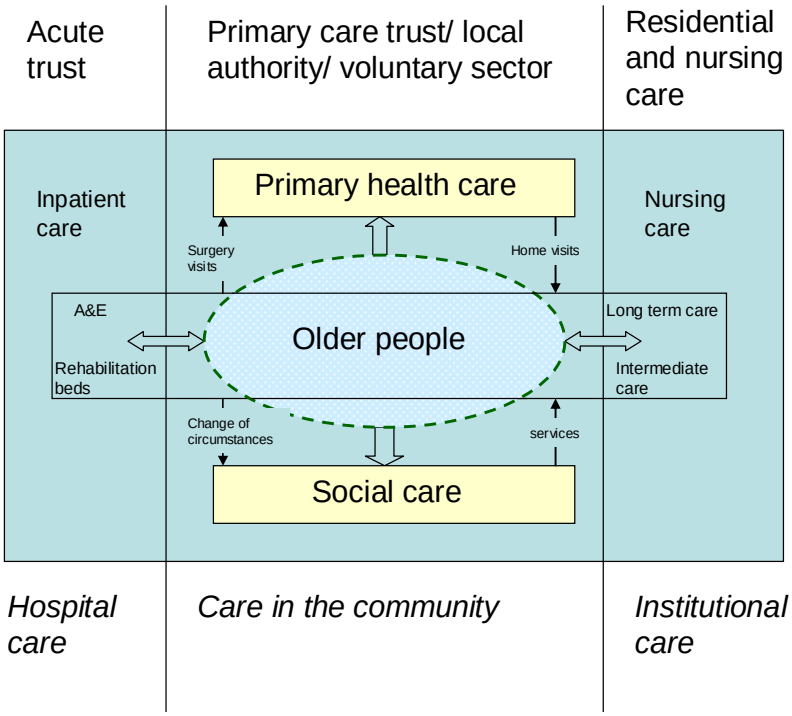
The separation of health and social care services is partly artificial but will have an impact not only in terms of co-ordination costs but also by other factors. Team working is often cited as the solution within small interdisciplinary teams and while this is obviously better than not working as a 'team', it can be seen as simply a different way of transacting information and tasks and not necessarily optimal in an efficiency sense.

A more fundamental problem is the logic of having lots of services and care specialists. Among the many different categories are community nurses, specialist nurses, occupational therapists, physiotherapists, social workers, GPs and many others. Over-demarcation is more likely to lead to staffing gaps, recruitment and retention problems, and higher co-ordination and management costs. These leads to gaps in service, delays and in the worst cases client neglect.

Consider the example of home visits. Each visit involves travelling between addresses for a contact time that lasts less than 30 minutes, so the time spent travelling will often exceed the contact time with clients in an over-demarcated system. A generic worker, for example, could take blood and provide catheter care, whilst helping with washing and dressing, and providing basic help with household finances such as payment of bills.

In principle this concept that should result in a better and more cost effective service to clients although it would need very careful design and testing to understand the levels of training required and new boundaries of authority that would need to change as a result. However, the contribution to productivity in combination with previous suggestions would be significant.

[44] Intermediate care




**Box 11: The local health and care economy from the perspective of an older person**

Many organisations and services may be involved in the care pathway of an older person within a range of care settings. These organisations could be statutory, voluntary or private either based in the community such as primary care provider or social services, a care home, or a large acute hospital.

Information is continually transacted between the person cared for and carers. Some information may be transacted between organisations but essentially all information is contained within organisational silos. The number of transactional boundaries increases with the number of care providers in the sequence: 0 (only one provider), 2 (two providers), ……, 12 (4 providers),……, 8 (56 providers) etc.

4.1.4 Support for carers

Numerous initiatives can be bracketed under the heading of support for carers. The following are ideas taken from range of sources and build on previously presented arguments and are listed in Table 8. They may be divided into two broad classes of support: either direct support for carers in their roles or support for carers in the workplace.

Direct support for carers in their caring roles divides into three smaller categories; the first of these, covered in A to D, are based on support in kind. They include for example advice on how to keep well and healthy, training in the techniques and methods of caring; information and advocacy to help carers with their rights and access to services, and safeguarding and protection from abusive relationships or low quality services.

Pickard[45] reviews some services available to support carers fall especially into category A but also B to D. Among her many findings she says that provision of day care and respite care (short breaks for either the user or carer) are associated with very high levels of satisfaction among carers; however, other types of respite services are less well regarded. For example, overnight respite in an institution or sitting services in the home do not appear to be as popular or as effective.

Pickard further observes that practical help and nursing care provided to people in their own homes and domiciliary care services are highly valued by carers and are the foundation for many care packages. Social work and counselling to relieve carer stress and support groups are valued but it is not clear how widely available these are.

The advent of 'personalised budgets' has created a new category of financial decision making on which carers would need advice in matters such as how to pay for and procure care. The second category of support therefore relates to financial matters such as advice on selling or releasing equity from a house in order, for example, to pay for care or on care home selection (E and F), or to obtain advice on benefits entitlement for carers or the person being cared for.

Personalised budgets already exist in the form of universal benefits such as Attendance Allowance. The concept is now being extended to allow greater freedom of choice in the form of cash payments or notional budgets, in which social services departments assess care needs and eligibility for financial support. This is been part of a wider trend which is also underway in parts of the health care system.

The question of whether to increase the scope of personal budgets has huge significance in terms of the way disabled and older people's lives are supported since it challenges many deeply entrenched divisions between:

- Health and social care
- Care and social security
- Means-tested and non-means tested benefits
- Universal, targeted and discretionary benefits
- Care, leisure, well-being, development and work
- National and local budgets
- Cash-limited and non-cash-limited entitlement-based funding

Because it puts choices in the hands of the people receiving care, it potentially changes the dynamic of many different agencies including Adult Social Services, NHS Commissioners and providers, and the Department for Work and Pensions and its various agencies. These divisions are legacies from past eras and may not be suited to future needs especially where they lead to conflicting behaviours and incentives. Some of the current terminology is also anachronistic (e.g. Attendance Allowance, a tax free benefit for people aged 65 or over who need help with care due to a physical or mental disability), and there is clearly scope for simplifying and making financial support more transparent.[46]

[45] Pickard, L., (2004). 'The effectiveness and cost-effectiveness of support and services to informal carers of older people'. Personal Social Services Research Unit. London: Audit Commission,

[46] One simplification would be to absorb Attendance Allowance within the State Pension which would pay a higher rate of pension when people became disabled.

Category G makes a different point which is about supporting these activities with better information on needs at a population level that will indirectly lead to better support for carers through having a proper and up to date evidence base for resource allocation and commissioning. It extends the concept in Section 3 of making much better use of local information assets for measuring populations and their needs. There are currently only a few examples of how this could work, one of which is the Brent study mentioned above.

The Health and Social Care Act sets out the Coalition Government's reforms for health services in England. It places a duty on local authorities to establish Health and Well-Being Boards, which are intended to lead on improving the strategic coordination of commissioning across NHS, social care, and related children's and public health services. Clearly, their duties will be frustrated and effectiveness diminished if there is an artificially imposed data 'iron curtain' between the participating stakeholders in this process which prevents information from being shared.

The work reported in Box 12 was commissioned by Tower Hamlets PCT. It involved joining together data sets from primary and secondary care, housing, benefits and social care data from the local authority. Data were linked via the NHS number and the Local Land and Property Gazetteer to provide a comprehensive picture of, in this case, the 65+ population. The full data base covering the whole population is currently being used for a range of purposes including laying the groundwork for local commissioning.[47]

Box 12 shows two examples that have been created to improve local health intelligence using linked data in this London borough. The map shows the locations of households in the 65+ population living in Tower Hamlets with each colour coded according to the number of primary care sites there are within a 10-minute walk time of each household. Such detail enables providers to calibrate precisely local needs and any gaps. In this case evidence shows that the farther an older person lives from a primary care provider, the less likely they are to visit a doctor leading to unmet need.

These kinds of maps show that Tower Hamlets is, on the whole, well provided with primary care services and that only a few areas have relatively restricted coverage (e.g. those households shaded in black). However, this is not necessarily the case once the example is extended to other kinds of publicly and private provided services that need to be accessible. These kinds of maps, the product of joined up information, enable gaps to be identified and at risk populations affected and fully enumerated.

Also contained in Box 12 is a table which profiles secondary care costs of the 14,975 people in the 65+ age group. The table is inclusive of all admissions over a three-year period, which has then been annualised according to the appropriate prevailing cost tariffs. The population has been segmented and enumerated into 16 mutually exclusive groups based on whether they live alone, are aged 75+, living in social housing or receive means tested benefits.

The totals at the foot of each risk factor show the prevalence of that risk factor in the population. The table ranks each sub-group from highest to lowest cost. The results show a clear cost gradient depending combination of risk factors applying to each

[47] For further details see this link taken from the Guardian: http://www.guardian.co.uk/social-care-network/2011/nov/09/tower-hamlets-social-care-health-data

risk group. By comparing rows we find that average cost of secondary care for someone with none of these risk factors (i.e. lives with another adult, is aged between 65 and 74, lives in a private dwelling, and is not on benefits) is £516 per person per year (row 15); but where a person is aged 75+ it increases by £420 (row 8), by a further £135 if receiving benefits (row 6), and by another £212 if living alone (row 1).

This information is being used to engage with local communities, health providers, the council and others to consider health needs, and how to deliver services more efficiently and effectively. A parallel study using social care was able to identify the number of people receiving services by risk group and area and has enabled the identification of the extent of unmet need among high risk groups, such as older people living alone.

The second category of support is for carers in the workplace. There are currently over three million working carers in the UK. Work is important for well-being, income and for maintaining social contacts. Working carers need a range of support in the workplace, and different levels of support at different times, from access to a telephone or to flexible leave arrangements.

Table 8, H to J, identifies three areas in which help for carers would improve their ability to combine work and care. These are help with finding jobs, financial help through the introduction of, say, a Care Credit, and support from employers. It is arguably in this third area that most progress has been made. The Work and Families Act 2006 and the Employment Rights Act 1996 for example gives working carers rights to help them manage work and caring including the right to request flexible work and emergency leave entitlement.

Since 2007 carers also have a right to request changes to their working patterns to better manage their caring. Employees also have the right to take a 'reasonable' amount of time off work to deal with an emergency involving a dependant. The arrangements also extend to parental leave. Providing a person has at least one year's continuous service with an employer and is responsible for a child aged under 5, or under 18, if that child is entitled to Disability Living Allowance, a parental carer is entitled to extended leave to look after a child of up to 18 weeks.

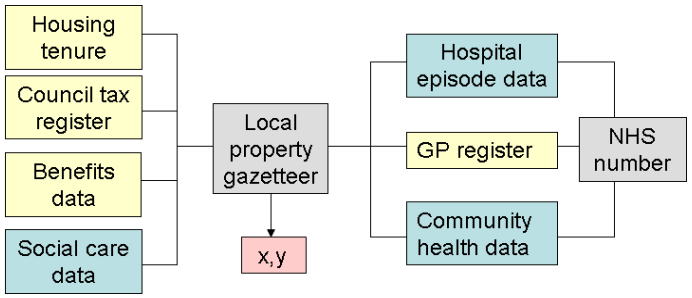
| | *Intervention type* | *Rationale* | *Comment observation* | *Carers have access to better more personal-ised services* | *Carers able to lead more indepen-dent life* | *Carers have access to financial support and advice* | *Carers enabled to remain mentally fit and healthy* | *Carers better informed* |
|---|---|---|---|---|---|---|---|---|
| **A** | **<u>Support for carers</u>**<br><br>Support for carers to stay healthy | Carers sometimes neglect their own health to look after others | Depending on type of support, these are typically interventions that free up carers' time. Care breaks are the most common request from carers | | | | ■ | |
| **B** | Training for carers | Carers can learns skills that support prevention, help to maintain independence as well as maintain their own health and safety | Can increase confidence of carers and willingness to accept support etc. Skills learned may be transferable, and marketable | ■ | ■ | | ■ | ■ |
| **C** | Information, advocacy and advice for carers | Carers may not be aware of their rights. They need to access many services but information is fragmented across public, private and voluntary sectors. Sources of information and advice not all equally trustworthy | Providing carers with the opportunity or skills to access information when they need to is helpful. Information needs to be easily accessible for all groups of carers, wherever they live. | ■ | ■ | ■ | ■ | ■ |
| **D** | Safeguarding and protection | Caring involves human contact. Both the persons being carer for and the carers may need safeguarding or protection at some point | Care system needs to be alert to abusive relationships, neglect, low standards of professional care and other negative outcomes | | | | ■ | ■ |

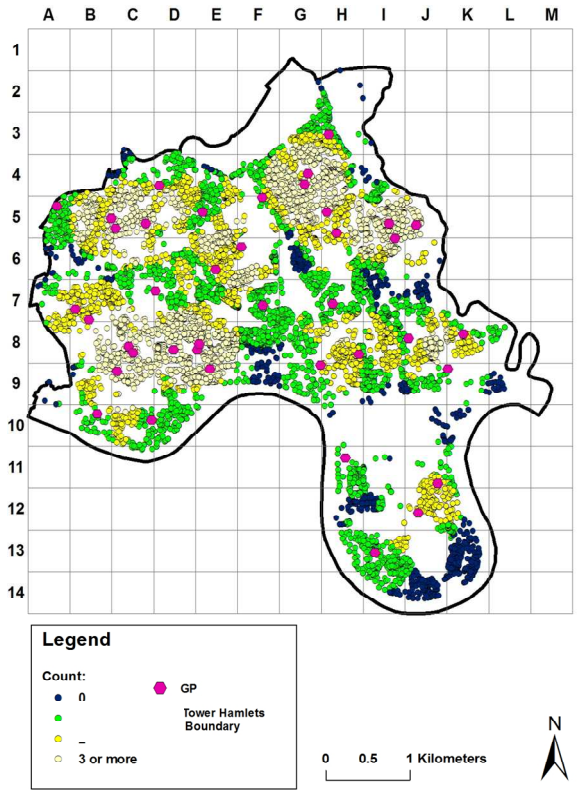
| | *Intervention type* | *Rationale* | *Comment observation* | *Carers have access to better more personal-ised services* | *Carers able to lead more indepen-dent life* | *Carers have access to financial support and advice* | *Carers enabled to remain mentally fit and healthy* | *Carers better informed* |
|---|---|---|---|---|---|---|---|---|
| **E** | **<u>Finance and resources</u>**<br><br>Financial advice at point of need | Except for health, most care must be paid for; carers are heavily involved in decision making but the financial issues such as releasing equity from home to pay for care are complicated | Currently there is a gap in the care economy for this kind of service; sign-posting services in local authorities, often the first point of contact, are uncommon and not part of the skill set. | | | ■ | | |
| **F** | Personalised budgets | Personalised budgets for persons carer for and their carers would lead to more flexibility in terms work versus care choices and for sourcing care | Needs to be clear on how budgets are calculated, and on how different budgets streams are merged and managed and their purpose. | ■ | ■ | ■ | | ■ |
| **G** | Include information on carers in local area needs assessment | Would enable inclusion of whole care economy in local plans and improved commissioning of services | Carers would be included in needs assessments and services designed accordingly. Key to this is joined up information at a population and person level. | ■ | | | | |

| | *Intervention type* | *Rationale* | *Comment observation* | *Carers have access to better more personal-ised services* | *Carers able to lead more indepen-dent life* | *Carers have access to financial support and advice* | *Carers enabled to remain mentally fit and healthy* | *Carers better informed* |
|---|---|---|---|---|---|---|---|---|
| **H** | **Employment support**<br><br>Help with finding jobs | For carers that want to work support in finding jobs and coping financially | Finding suitable jobs whilst caring is time consuming and difficult to organise | | ■ | | ■ | |
| **I** | Introduction of Care Credit | To enable carers to combine caring with paid work to enable smoother transition from work to care and vice-versa | Work does not pay or may not be available for many carers even if they would like to work so that they are not trapped on benefits. Low value of benefits and restrictive or petty rules a common source of complaint among carers | | ■ | ■ | | |
| **J** | Employer support | To enable carers to balance work and care and to get back to work once spell spent caring has finished | Depending on type of support there are many ways a carer could benefit from employer's support (e.g. flexible hours, home working, training, leave of absence) | | ■ | | ■ | |

*Table 8: Initiatives designed to give support to carers*

| | Population age 65+ | A living alone | B aged 75+ | C living in social housing | D receiving benefits | admissions per 000 per year | cost per head of population in sub-group per year (£s) |
|---|---|---|---|---|---|---|---|
| 1 | 418 | Y | Y | | Y | 617 | 1283 |
| 2 | 1571 | | Y | Y | Y | 628 | 1148 |
| 3 | 542 | Y | Y | | | 621 | 1107 |
| 4 | 1595 | Y | Y | Y | Y | 562 | 1092 |
| 5 | 439 | Y | Y | Y | | 590 | 1073 |
| 6 | 851 | | Y | | Y | 587 | 1071 |
| 7 | 470 | | Y | Y | | 613 | 996 |
| 8 | 901 | | Y | | | 578 | 936 |
| 9 | 1229 | Y | | Y | Y | 479 | 834 |
| 10 | 297 | Y | | | Y | 499 | 826 |
| 11 | 2385 | | | Y | Y | 472 | 720 |
| 12 | 1175 | | | | Y | 456 | 701 |
| 13 | 567 | Y | | | | 372 | 667 |
| 14 | 302 | Y | | Y | | 323 | 639 |
| 15 | 1546 | | | | | 434 | 516 |
| 16 | 687 | | | Y | | 341 | 505 |
| total | 14975 | 5389 | 6787 | 8678 | 9521 | 511 | 862 |




**Box 12: Joining health and social care data together to analyse primary and secondary care**

Administrative data are joined together using a person's NHS number and Local Property Gazetteer. The 65+ population is mapped according to ease of access to GP services to identify potential gaps and duplication. The 'at risk' population is segmented into 16 risk groups in order to determine annual average cost of secondary care. Taking all risk groups together and averaging their effects, the cost with no risk factors is £551 per person per year; if aged 75+ it increases by £393, if receiving benefits by a further £157, if living alone by £91. Social housing has negligible or no effect on cost in this age group.

# 5. The future for carers

## 5.1 Backdrop

The UK economy is likely to grow more slowly in coming years due to global shifts in economic power and changes to its demographic structure. The ageing population itself can be regarded as the demographic dividend of a long period of improved standards of living, increases in personal wealth and universal access to health care and education, and improved opportunity for all. Changes in family structures, the emergence of pivot generations, wide variations in income and wealth and increased cultural diversity make for an increasingly complex care economy.

Population data for the UK show that ratio of people aged 20-64 to those aged 65+ peaked in 2008 at 3.7 and is now in long term decline and set to reach 2.5 by 2030, so there will be fewer younger adults to provide potential support. A support ratio based on the number of 20-79 year olds to those aged 80+, falls from 15 to 9 over the same period. This not just an issue confined to the older population as young adults with disabilities are also tending to live for longer so their numbers will also increase in future.

With the frontiers of the welfare state receding in areas such as social care and benefits, it will fall to families and households to absorb a majority of any additional burden either financially or through providing care in kind. There are major changes ahead to which the outlook for carers will be strongly tied. These include acceptance of the recommendations of the (Dilnot) Commission on Funding Care and Support, wider benefits reforms for example to Disability Living Allowance which will become the Personal Independence Payment, and the introduction of the Universal Credit, and NHS reforms.

There are a number of related issues that will also impact on the care economy. These include the future role of local authorities in the assessment and delivery of social care, issues to do with adequacy of the supply of care workers, their levels of training and the quality of care provided. There are concerns regarding variations in geographical access to care, means testing, access to information and so forth. The overall direction is towards greater individual responsibility and local decision making.

A crucial element is the relationship between social care and the NHS. It has been argued that the practical effect of trends in care assessment towards only providing support for those in greatest needs coupled with early discharge from hospital has left more people facing crisis situations. However, the evidence points in the direction of providing more preventive services and earlier intervention as a means of managing future demand.

The social impact of these changes can be mitigated if people work for longer and there are jobs for them to do. However, they also need to remain healthy for longer because healthy people are more likely to be in work and better health implies fewer carers. This requires changes of behaviour at an individual level but also new mechanisms that reward health or reduce future health and social care costs.

Carers will be on the receiving end of these shifts in policy and changes in funding. It follows that steps set out in this paper will work best if there is clarity about how social care is to be financed in the future, closer working between health and social care, as well as access to better information and advice.

### 5.2 Underlying themes

It is generally accepted that carers must be involved in decision-making alongside the person they care for. In this way carers are empowered to take control of their lives and to do what is best in particular circumstances. Standing back from the detail, what then are the themes that emerge from the research that will directly impact on carers? It is appropriate to consider these under two broad headings: support for carers and families, and access to services and technology.

It is important not to undermine the autonomy of care users. Carers need to be supported through often complex care pathways with financial and other advice and where appropriate training. The analysis presented here suggests that there are wider economic benefits that would result but other inducements are need to make work more accessible and more flexible. It is hoped that the benefit reforms underway will address the some of the limitations of Carer's Allowance who also receive Income Support and replace it with a better system with more appropriate incentives if carers can work. However, this aspect of welfare reform proposals is as yet under-developed.

A related theme is that in some cases the responsibilities which carers are expected to shoulder is too great. This applies especially to those for those caring for children, working-age adults and those with complex conditions. Support can take many forms and access to respite care is judged to be one of the more beneficial forms of support that can be provided. In this regard, as has been noted, there have been some improvements in the rights for carers which amount to improved support.

Turning to services, it is generally accepted that older and disabled people want to live independent lives at home or in sheltered housing of their choice for as long as possible. A key challenge therefore is how to offer low-cost solutions from multiple providers which are personalised to meet the service users' needs. This requires much better information built around individuals receiving care as well as the organisations providing the care and housing organisations.

Medium and long term changes are required to improve efficiency and the quality and range of services. There is a recurring theme about the economic value particularly of low level interventions and whether these should be funded by the state. The pattern of the past is for seed corn funding to be provided to support different initiatives but these tend to wither away once the funding is exhausted. In this way a lot of resources are arguably wasted and expertise lost.

We identified low or stagnating productivity in the caring economy as one of the key challenges. Inefficient information sharing between providers and carers limits the scope for closer working and care planning. A consequence is that services are not as integrated or as efficient as they could be. One of the issues identified was the potential for over-demarcation of roles and responsibilities of care providers. Designed to improve professionalism and quality of care, demarcation can lead to unintended consequences such as poor co-ordination and lower productivity so there are trade offs to avoid excessive fragmentation.

How unpaid care is organised could also be improved in tandem with improvements to mainstream services. Unpaid care could be better supported by local authorities without them necessarily being responsible for the care they provide. For example, 'time banks' enable individuals to earn 'time credits' for hours of voluntary work. These formalise reciprocity and facilitate volunteering. Although relatively new they have become popular and now operate in a number of countries.

Although they cannot be regarded as full substitutes for face to face contact, assisted living technologies offer the potential for improved quality of life for people who are confined to their homes. These are designed to deliver services which entertain, educate and stimulate social interaction, provide services which encourage users to get fitter and to adopt healthier lifestyles (wellness services) and enable older and disabled people to work from home (teleworking services).

## 5.3 Barriers to change

It can be argued that there are almost as many barriers to change as there are opportunities for change. These include behavioural barriers such as attitudes to staying healthy and general ignorance about the care system as well as institutional barriers that are barriers to greater efficiency and improved outcomes. Perhaps the biggest barrier is inertia which is the result of long term custom and practice, perceptional barriers and the complexity of the system.

Some barriers transcend politics and are common sense. Helping people to stay healthy for longer is not a panacea but there are clear links between the demand for care, health and ability to work, all of which in turn are depend on family resilience, education, access to health care and opportunities in life. We have commented on the reasons for economic inactivity especially among people in their 50s and early 60s, including long-term health problems, lack of skills or qualifications, but also people forced into economic inactivity because of caring responsibilities.

At the day to day level, a barrier pervading the whole care sector is systems complexity, some of which is inevitable and some self-inflicted. An important barrier is the lack of information about the population needing care but also carers themselves, especially information that is specific to an area or locality that would enable better case finding and prevention services or opportunities that would improve carers' lives. Local information about carers is only obtainable through the 10-year Census, and so this can only ever provide a limited snapshot and one that is out of date before it is even published.

What is needed is a much more intelligent use of local administrative information and some examples have been given. A distinction can be drawn between uses of data about individuals and for example their use in individual care records and statistical uses of administrative data for planning purposes. More effective use of administrative data is hindered by artificial organisational boundaries and multiple interpretations of data protection legislation including misplaced views about privacy and confidentiality.

Better data sharing is of key importance for the effective introduction of preventive services that for example reduce unscheduled hospital admissions. To succeed such programmes require good case finding procedures and joined up care records; for example, there was evidence of people referred to the Brent service that would not have been identified by social services until the point of crisis, typically older people living alone or on benefit with no family carer. Similar findings were obtained in the Moffat project in Glasgow.[48]

[48] T. Kelly et al (2010). 'Preventing Crisis for Carers – Moffat project'. Final Evaluation Report.
Glasgow Caledonian University. A Princess Royal Trust for Carers' Programme, Funded by the Moffat Charitable Trust.

Currently, information needed to support prevention work is sparse and disjointed. Each organisation involved in care maintains separate records on hospital admissions, community health visits, and care packages all of which could be easily unified using NHS numbers into a singly sourced care record. The immediate impact of this would enable better case management, care plans and an ability to tailor support packages in the home or other settings.

Prevention services work better if they are timely and faster reacting. Transitions into care and then subsequently into end of life care can occur suddenly and are times of heightened stress for carers. With funding pressures in local authorities it can be argued that the incentives are the exact opposite to what is needed, i.e. to delay assessments and raise the thresholds at which social care is provided. This is counterproductive if the result is to increase the needs for crisis interventions and greater healthcare costs.

The lack of joined up information has another perverse effect which is that it is difficult to assess the value of preventive services and low level services are often the first to be cut when there are funding pressures. Providers argue over the attribution of benefits to particular services or interventions, they are concerned about 'deadweight' cost of services that would have been taken up anyway and about long term benefits, or, crudely put, investing in services for people that only have a limited time left to live.

Barriers to the wider adoption of ALTs, it seems, are partly technical and partly cultural. Technically it is important to ensure that basic broadband is made available in all areas as soon as possible but especially rural areas. We know that generations approaching the dependency phase of life will be more technology literate than their predecessors. But another barrier to their adoption lies with care providing services, since there is almost no expertise in the use of assisted living technologies by the caring professions and poor information about the return on investment.

We have noted that the demand for unpaid care is a function of what the state is prepared to provide, what people can afford and are willing to pay, and also personal preferences such putting caring activities ahead of employment opportunity. The present disadvantages faced by those caring intensively mean that it may be better to encourage many more people to care less intensively rather than encouraging those that care in increase the hours they provide.

However, there are barriers of a financial kind that make it unprofitable to work without some addition financial support either to pay or systems such as time banks are a resource for sharing caring duties. The limited nature of Carer's Allowance does little to help people stay in work and could be replaced, as has been argued in this research, by a Care Credit that would support those who also had to meet care costs out of pocket. Currently, Carer's Allowance does not take account of carers who care for more than one person, whilst the overlapping benefits rule means that a person cannot be paid Carer's Allowance while receiving other income maintenance benefits.

The enablement of flexible working would encourage a greater number of people to take on caring responsibilities in addition to working, so increasing the pool of low intensity carers and encourage a wider spectrum of people to be carers. For carers who have withdrawn or have been downgraded in the labour force, there is often a need for additional support (access to employment services, education and training) to get them back in the job market.

The Work and Families Act 2006 and the Employment Rights Act 1996 were major steps in the right direction. These gave working carers rights to help them manage work and caring including the right to request flexible work and leave entitlement for parents; the right to time off in emergencies; and with sufficient notice. More far sighted employers are recognising that going beyond the statutory minimum has sound economic benefits.

In summary, a good outcome for carers is one that meets their needs as well as the needs of the person being cared for. These outcomes can be measured in financial or career terms in cases where work and caring are balanced or in emotional terms, in terms of duty of care real or otherwise, or in terms of the health and well-being of the carer. However, progress in achieving better outcomes can be frustrated by the institutional complexity of the system and the tensions that exist between Government Departments, agencies and public services, but chief among these are the interfaces between health and social care.

**Annex A: Family structure and carer pool over the life cycle**

This annex summarises an investigation using a mathematical model into the potential availability of carers over typical life cycles drawn from family structures based on different births year of women from 1931 to 1961. It is based on the observation that care needs are highest in the early and later years of life, life expectancy has advanced significantly, and that birth parity among women is varied. The assumptions are as follows (although these can be varied in the model)

Assumptions

1. The pool of care givers includes parents, siblings and children (grandparents are not included, since assumed more relevant as carers in a person's early years except in example 4. In-laws and grandchildren are also excluded.)
2. Male and female life tables for given birth years are used to 'age' individuals in the model (source: Human Mortality Data Base)
3. Minimum age to be a carer is 18 years (this can be varied in the model)
4. Maximum age to be a carer is 75 years (this can be varied in the model)

Findings

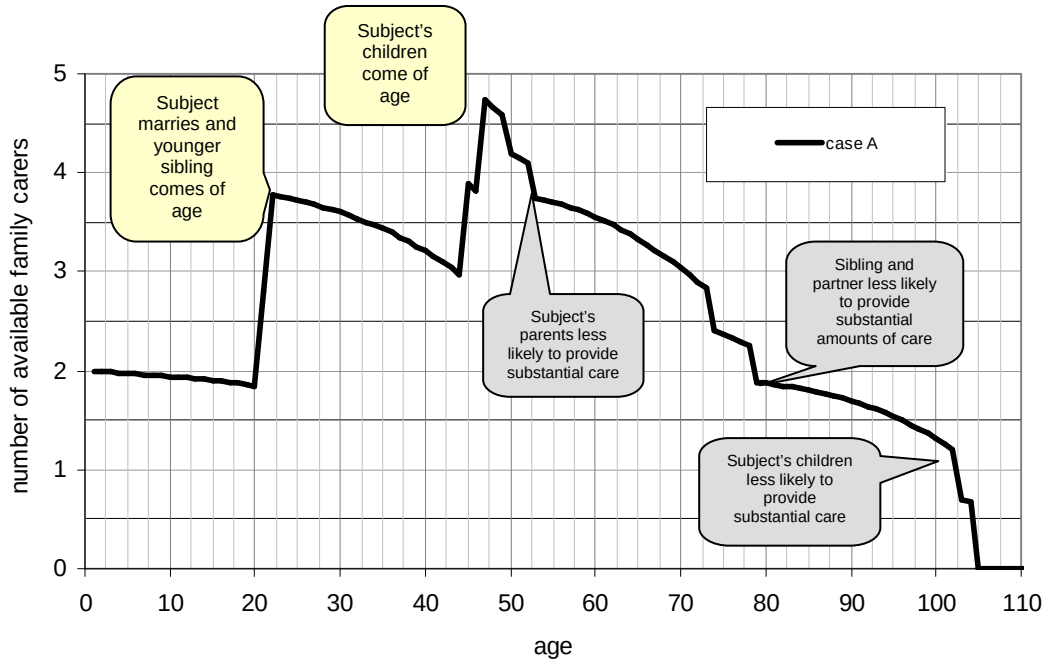
Certain family structures severely restrict the availability of carers in later life. Other structures result in a temporary reduction or changes in the periods that family carers are available. A powerful determinant of the size of the family pool is marriage (or partnering), and the number of children and siblings. The care pool is increased when grandparents are included, but their role is more important during the early years of life.

People without children, particularly those that are single, will have no available carers beyond the age of 80 (as partners/siblings will be less likely to be able to provide certain levels of substantial care or will have died). This is also the time when their care needs are likely to intensify. So there is extra concern is for those who are not married, or without a long term partner and who have no children, or were very young when they had their children, or who live to very old ages.

The following are some examples. In each case the pattern is compared with a reference example shown earlier in the main text (Box 5) and below and which we call case A. This example is of a woman born in 1961 to parents who married in their 20s. She has one sibling, marries in her early 20s to a man who is slightly older, and has two children before she is 30 years old. We now contrast this reference family with other family structures to evaluate the differences.

Reference Case (A): Married, one sibling, two children

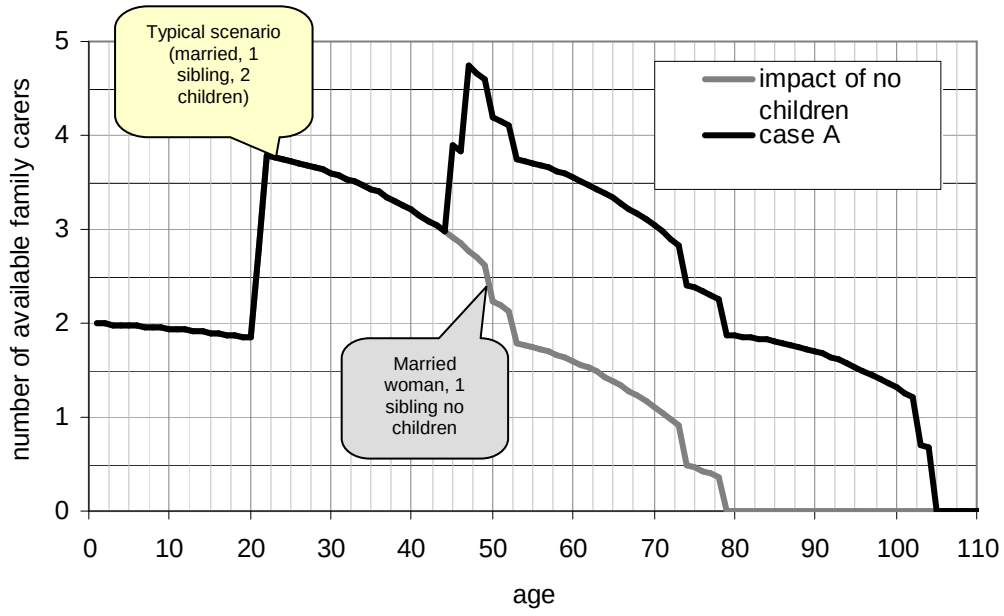
The reference case (A) is for a married woman with two children. The graph shows the average number of available family carers available to the woman throughout her life. Reasons for changes such as marriage or a child reaching the age of 18 is labelled on the graph at the appropriate points and represents assumptions about age of onset of frailty etc. Typically the maximum availability of family carers in such cases is between ages 20 and 60.



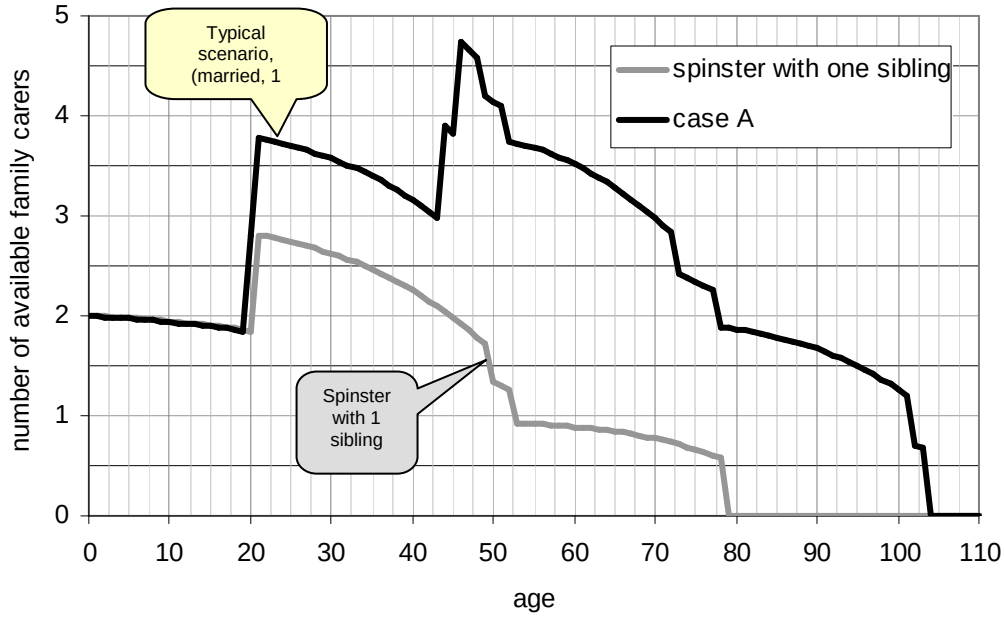

*Reference case A*

<u>Example 1: Woman without children</u>

Example 1(i) is for a married woman with no children and one sibling. Example 1(ii) is for a never partnered woman with one sibling. In either case the life time availability of carers is severely curtailed.



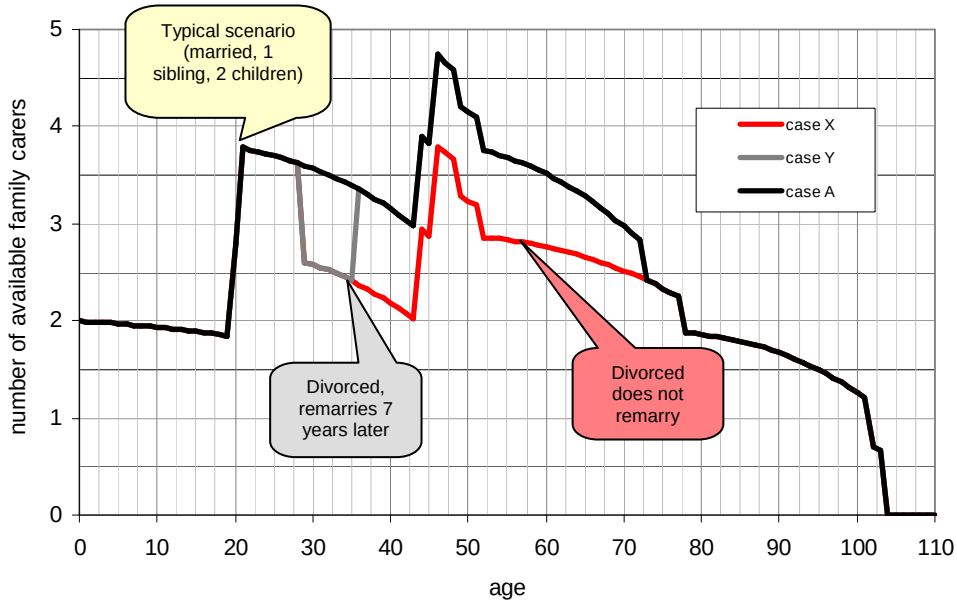

*Example (1): (i) Married woman with no children and one sibling*




*Example (1) (ii) Never-partnered woman with one sibling and no children*

Example 2: Marriage and re-marriage

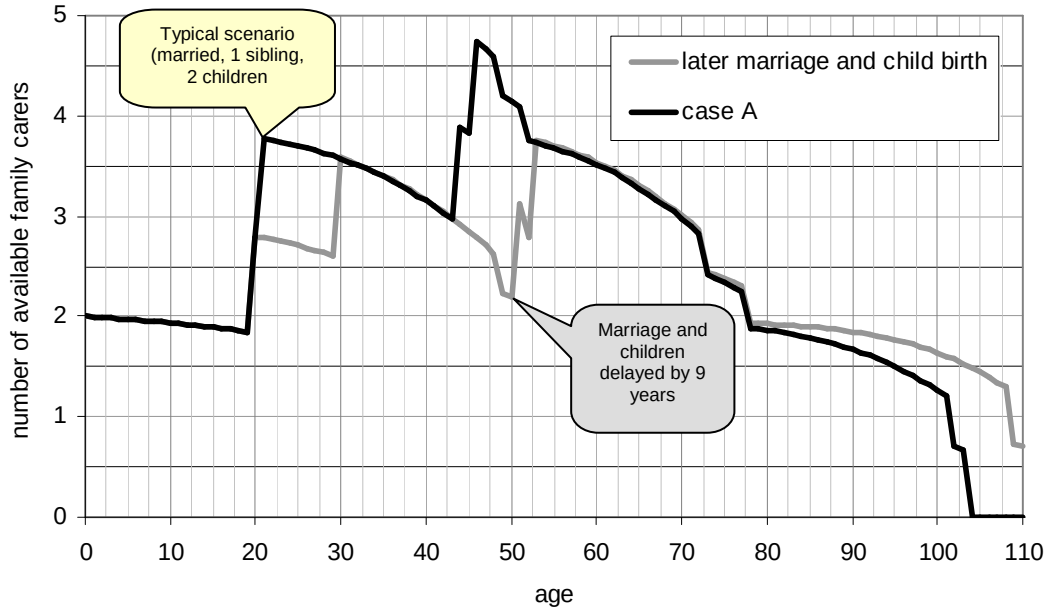
Data show that people are living longer, having children later but also divorcing and re-marrying. Example 2 explores the impact on the size of the carer pool versus the reference family. Case X is a woman with two children and one sibling that divorces before age 30 but does not re-marry; Case Y is a is a woman that also divorces but then re-marries 7 years later.




*Example 2: Case X, a woman with one sibling and two children who divorcees before age 30 but does not re-marry; Case Y, same woman but who remarries 7 years later*

Example 3: Effect of delayed marriage and child birth

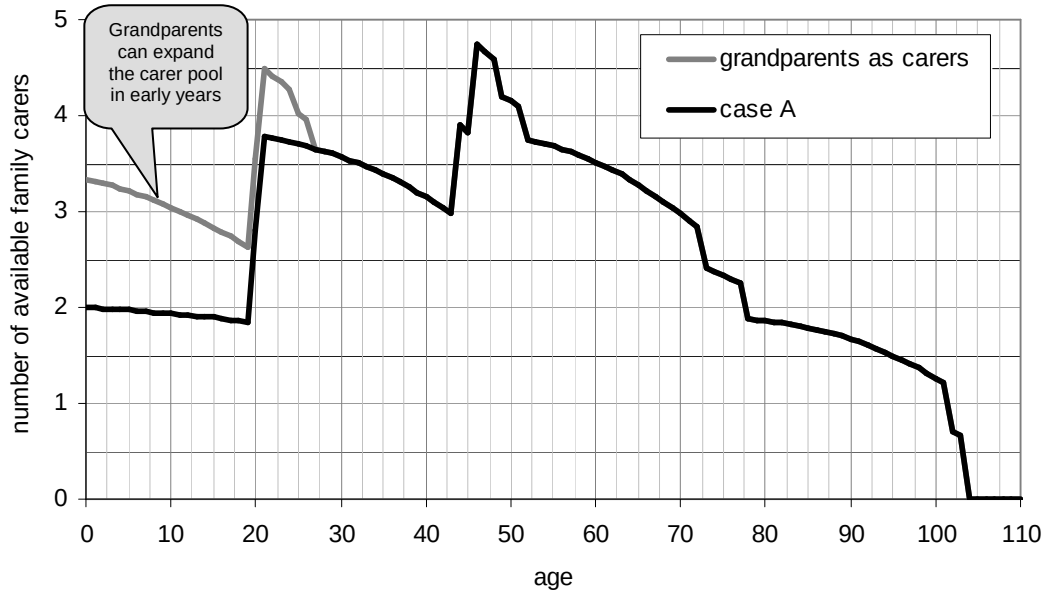
Example 3 shows the effect of later marriage and child birth. The result is a delay in the addition of the marriage partner to the family carer pool. There is a further dip in carer availability in a woman's early 40s to 50s as her parents become less likely to be able to provide substantial care and her children are not yet 18. However, she could benefit from having more carers available to her at the end of life.




*Example 3: The effect of delayed marriage and later child birth*

Example 4: Grand-parenting

Grandparents are be added to the family pool in example 4. Grandparents are especially important in a child's early years.




*Example 4: Reference case including the impact of grandparents*

**Annex B: Carer's Allowance**

To be eligible the following conditions must be met:

- The person being looked after receives a qualifying disability benefit
- Care is provided for at least 35 hours a week

Also the carer is:

- aged 16 or over
- not in full-time education
- earns less than £100 a week after deductions
- satisfies UK presence and residence conditions

For each person cared for only one Carer's Allowance may be paid even if caring is shared between two or more people.

There is no upper age limit for claiming Carer's Allowance; however, the State Pension is classed as the same type of benefit and only one can be paid at the same time, whichever is higher. However, an underlying entitlement to Carer's Allowance is maintained in which case a carer could receive the Carer Addition to their entitlement to Pension Credit.

Carer Premium and Carer Addition

The Carer Premium is extra money included in the calculation of income related benefits such as Income Support, Job Seeker's Allowance, and Council Tax and Housing Benefit. It is awarded to people that meet the qualifying conditions for these benefits and who also receive Carer's Allowance or an underlying entitlement to Carer's Allowance. The Carer Addition is an equivalent amount paid with Pension Credit.

Other entitlement rules in brief

- Carer's Allowance is paid for up to 12 weeks if a carer goes into hospital
- Carers may take a respite break from caring for up to 4 weeks in every 26 weeks
- Carer's Allowance can be paid for up to 26 weeks when they travel abroad if they accompany the person being cared for
- If the person cared for moves into residential care then Carer's Allowance is paid for a further 4 weeks and the Carer Premium or Carer Addition for eight weeks.
- If the cared for person dies, Carer's Allowance, Carer Premium or Carer Addition may be paid for eight weeks assuming the wider rules are met

Passported benefits

Entitlement to Carer's Allowance is linked to entitlement to other social security benefits such National Insurance Credits and Xmas Bonus. Other help for carers is at the discretion of local councils and employers and are not linked to Carer's Allowance entitlement.

**Annex C: Distribution of income and wealth in the 65+ population**

Section 1.5 analysed the affordability of longer term care among the older population. Unlike health care the cost of social care is the responsibility of individuals except where an individual's assets falls below £23,350 in which case they may be eligible for state help. In considering ability to pay, it is important to take into consideration both income and wealth.

This annex is designed to exemplify the discussion in section 1.5 to paint a picture of how income and wealth in the 65+ population is distributed. Using data from ELSA, we created a map of people's income and wealth. Chart C1 is a contour map of individual assets (shown on the vertical axis) and income (on the horizontal axis) in which each contour represents 10% of the population aged 65+.

Because of the State Pension, Pension Credit, other benefit entitlements and personal pensions, modal incomes are around £11,000 per year. Assets on the other hand are strongly influenced by home ownership and the chart shows a wide distribution of wealth that tends to cluster in two places: those with assets of around £100,000 (home owners) and those with rather less £5,000 - £10,000 (non-home owners).

If income and assets are pooled it is possible to calculate the notional number of years that an individual could afford to pay for long term care. The worst and most expensive situation arises when a person is transferred to institutional care in which case out of pocket costs are typically greatest, unless a person is eligible for free continuing care under the NHS.

Assume for illustrative purposes that long terms care costs £25,000 a year. The chart splits the population into five bands: A to E. A person situated in band A could afford care for less than one year, in band B from one to two years and so on to band E, for four to five years. A person situated anywhere else on this chart could notionally afford care for more than five years based on the same calculation.

The chart shows that a majority of people could afford care for five years (in fact 68.5%) but there are significant numbers of people trapped in band A the lowest category (20.7%). Access to finance to fund care can depend on the sale of the main home, although other types private finance alternatives are possible and to some extent available, including pre-funded insurance, disability linked annuities, immediate needs products.

However, the underdeveloped market for private finance products is an important barrier to bringing new money into the care system. The problem is that each situation is different and users need a range of products to suit their needs and attitude to risk. They need advice on what is best for them, assurance that the Government is not going to renege on its funding policy, and appropriate incentives to buy suitable products. These issues, including worked examples of financial products, are discussed in Mayhew L., Karlsson, M., Rickayzen, B. (2010).[49]

[49] 'The Role of Private Finance in Paying for Long Term Care', Economic Journal, 120(548), p.F478-F504

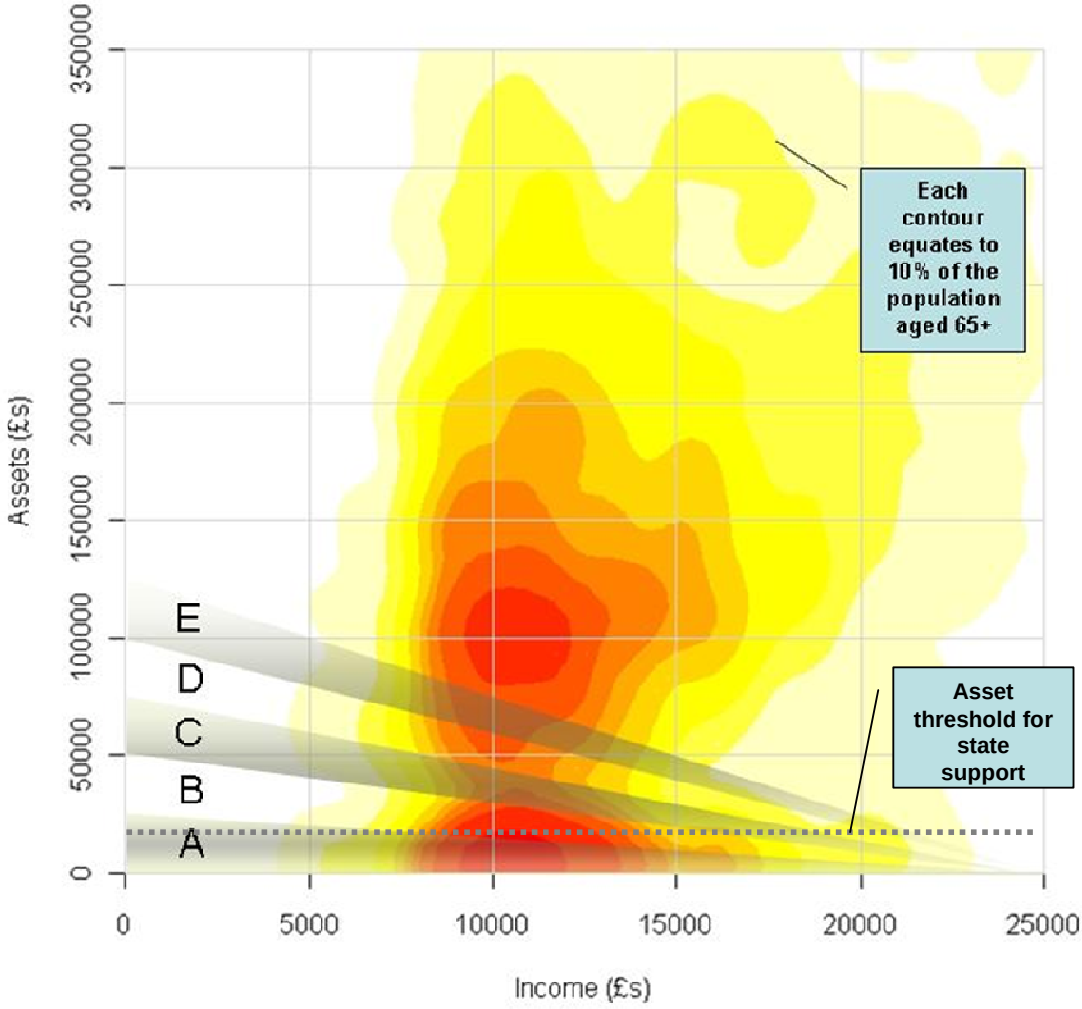



*Figure C1: Chart showing map of income and assets in the 65 and over population. Each contour represents a 10% increment of the 65 and over population. The darkest shaded areas of the map indicate where most people cluster. Bands A to E contain people that can afford care for five years or less (see text). The horizontal bar shows the current capital limit for state assistance for paying for long term care, currently £23,250*

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